

**A PHENOMENOLOGICAL UNDERSTANDING OF THE
EXPERIENCES OF YOUNG ADULT STROKE SURVIVORS**

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DECLARATION

I, SUMAYA JEEWA, IDENTITY NUMBER 880617 014 5082, HEREBY DECLARE THAT:

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2. This thesis has not been submitted for another degree or for examination purposes at any other university or institution.
3. This thesis does not include any other person's data, pictures, graphs, symbols, or other information, unless specifically acknowledged and appropriately referenced.
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ACKNOWLEDGEMENT AND DEDICATION

All Glory is to my Creator, Allah (S.W.T), The Almighty, The Superior and The Sovereign, who has blessed me with abundant opportunities and guidance throughout my life and for providing me the courage, strength and patience to face the tasks put to me.

TO:

My unconditionally loving husband, who has been my pillar of strength, my voice of reason and the motivation behind my every success.

My parents and sister who have shared with me all that they have been blessed with.

All those who played pivotal roles in my recovery; I dedicate this thesis to the fervent effort you made.

The young adult stroke survivors everywhere: to our petrifying experience, followed by a lifetime of gratitude, appreciation and privilege.

ABSTRACT

Little is known of the experiences of young adults who have survived a stroke. This study explored the lived experiences of young adult stroke survivors. Four stroke survivors, between the ages of 18 and 37 years old were interviewed using an Email Facilitated Qualitative Interview schedule. The time elapsed since the participants' stroke was, on average, 4.5 years. The data was analyzed using Interpretive Phenomenological Analysis, which revealed five superordinate themes. These were (1) the initial response of shock and surprise, (2) frustration due to limitations, (3) perceived fear of judgment, (4) the significant role of family support, and (5) stroke as a journey of transformative learning. Overall participants described their experience in the recovery trajectory as exceptionally challenging and difficult; however, they viewed the stroke journey as a valuable learning experience. In support of the findings, it was recommended appropriate emotional, psychological and educational support be provided to young adult stroke survivors and their families.

INDEX – ABBREVIATIONS

CVA	Cerebrovascular Accident
EFQI	Email Facilitated Qualitative Interviews
IPA	Interpretive Phenomenological Analysis
SA	South Africa

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CHAPTER ONE: INTRODUCTION AND BACKGROUND

1.1 INTRODUCTION

The following chapter provides an introduction to the study, background to the research problem, the context of the research problem and the motivation and rationale for the research. The principal aim and objectives are presented in addition to the research questions and limitations of the study. Research methodology and theoretical framework are briefly introduced in this chapter; however, it will be elaborated on in Chapter Three.

The focus of the study is to explore young adult's stroke experiences within a South African context. Cerebrovascular Accident (CVA), commonly known as stroke, is fast becoming common in young adults for various reasons (Groppo et al., 2012; Kristensen, Malm & Carlberg, 1997; Lawrence, 2010; Murray & Harrison, 2004).

According to the Heart and Stroke Foundation a stroke is defined as:

"a disease that affects the blood vessels in the brain. It occurs when blood vessels carrying oxygen and nutrients to part of the brain suddenly becomes blocked or bursts. This means that part of the brain can't get the blood (and oxygen) it needs, so the affected brain cells die and parts of the brain may be permanently damaged, causing the person to experience the symptoms of stroke. It is very similar to what happens in a heart attack, so is often referred to as a 'brain attack'."

(<http://www.heartfoundation.co.za/what-stroke>)

For the purposes of this study, CVA will be referred to as 'stroke'. The definition above provides a framework of understanding of what stroke is.

Connor, Modi & Warlow argued that the "prevalence of stroke in South Africa is already as high as in high-income countries" (2008, p. 355). These scholars found that the mean age of stroke patients was younger for blacks than for whites in South Africa, which meant that more young South African blacks presented with stroke than young whites. Maredza et al. (2015) argued that only a few studies on epidemiology of stroke in South Africa have been published. Following deaths caused by HIV/AIDS, heart disease and stroke are the second most common causes of death in young adult South Africans.

There are several risk factors of stroke that need to be considered in addition to the types of strokes and consequences of strokes.

1.1.1 Risk factors of stroke.

Factors that are likely to increase the chances of strokes in young adults are for example family history of stroke, hypertension, high cholesterol, cigarette smoking, diabetes, obesity, excessive alcohol consumption, depression, pregnancy, blood clotting disorders, autoimmune diseases, and dehydration (www.heartfoundation.co.za/who-can-have-stroke). Maredza, Bertram & Tollman (2015) found that in South Africa raised blood pressure could be the most significant underlying factor contributing to stroke. Hypertension, diabetes, excessive alcohol intake, smoking, inadequate fruit and vegetable consumption were amongst the most common reasons for the high incidence rates of stroke (Kahn & Tollman, 1999; Van der Sande, Inskip & Jaiteh *et al.*, 2001; Walker *et al.*, 2000 as cited in Kolapo & Vento, 2011).

Similarly, Connor & Bryer (2006; p.195) assert that “urbanisation is predicted to increase the risk factors for vascular disease and hence lead to a sharp increase in stroke”. Stroke is an important cause of disability among adults and is one of the leading causes of death worldwide (Connor & Bryer, 2006; Ghandehari & Moud, 2006; Groppo *et al.*, 2012; Kumar, Kalra & Goyal, 2011). The condition results in the brain not receiving adequate oxygenated blood to function properly.

In addition to the aforementioned risk factors, some people carry the gene that promotes blood clotting, called Factor V Leiden Mutation. Two types of deficiencies may contribute to thickening of the blood, which may lead to clotting: Protein S and Protein C deficiency (www.mayoclinic.org). These genetic factors and deficiencies are detectable only through specified pathology testing, upon request by medical practitioners.

Having mentioned some of the possible risks factors, Kumar, Kalra & Goyal (2011) have indicated research into the causes of strokes may yield different results. They maintain the differences in findings can be attributed to ethnic composition, methodological differences in studies conducted, and differences in the available health facilities that influence case management, treatment and prevention strategies in terms of risk factors and the promotion of a healthy lifestyle.

1.1.2 Types of stroke.

There are two known types of strokes, namely ischemic and hemorrhagic strokes. An ischemic stroke is similar to a heart attack except that it occurs in the blood vessels of the brain. It is when an artery has been blocked mostly due to atherosclerotic build up on the walls of the artery, which results in the formation of a blood clot. Blood clots may form in the blood

vessels of the brain, or in blood vessels leading to the brain, or even in blood vessels elsewhere in the body, and then may travel to the brain. When these blockages or clots occur, a portion of the brain is deprived of vital oxygen-rich blood, and this may lead to permanent damage within minutes, followed by necrosis (death of tissues) (www.heartfoundation.co.za/what-stroke). Approximately 80% of all strokes are reported to be of the ischaemic type and commonly occur among the young (Connor & Bryer, 2006). According to Connor & Bryer (2006) stroke among the young are mostly associated to ischemic stroke.

A hemorrhagic stroke occurs when a blood vessel or artery breaks or ruptures in the brain. This causes blood to seep out of the blood vessel or artery and onto the nearby brain tissues, resulting in necrosis (death of tissues). The most common causes of hemorrhagic strokes are high blood pressure and aneurysms, which are weakened or thinned blood vessel walls.

1.1.3 Consequences of stroke.

Numerous complications are associated with stroke and their presentation is unique to each survivor. These complications associated with stroke may cause neurological damage, disability or death. The extent of the damage caused by the stroke depends on the area or areas of the brain that have been effected, and the time lapsed until appropriate treatment is sought. Syndromes of stroke include, among others, numbness, tingling sensations, paralysis (partial or full), cognitive impairment, weakened muscles, impairment in affect regulation, speech impairment, sight impairment, hearing impairment and sensation loss (www.heartfoundation.co.za/what-stroke).

1.2 MOTIVATION AND RATIONALE FOR STUDY

Within a South African context, statistics indicate that approximately 8760 strokes are experienced among young adults annually (www.heartfoundation.co.za/what-stroke). In the UK, approximately 4650 strokes have been reported among the young (Bevan, Sharma & Bradley, 1990). Since stroke is becoming more common among young adults, the interest of the topic of the lived experiences of young adult stroke survivors was one of the motivating factors for the selection of the topic to be explored. This area of study also holds a special and personal meaning to the researcher, which is detailed in the section below, thus the interest in stroke survivorship. Additionally, the researcher was encouraged to explore the experiences and make a contribution to the existing literature. Moreover, possible interventions that emanate from the study will inform health care professionals on treatment of stroke survivors.

The research question that guided this study was “what are the experiences of young adult stroke survivors?”

Murray & Harrison (2004) emphasise that qualitative studies in which stroke survivors provide accounts of their own experiences is lacking. They add that when conducting a study of this nature, it is important to note that adult stroke survivors should be treated as experts on their own experience. The aim for future research, according to these researchers, should be to explore the perspectives and experiences of the individuals. Hence, the researcher was motivated to undertake this research to contribute to the existing body of knowledge available pertaining to young adult stroke survivors’ experiences, and to further indicate how existing literature leads to the present research by highlighting the gaps in knowledge regarding this topic.

Another important factor in this research study was the researcher’s own personal experience of the topic being explored. This experience afforded the researcher the opportunity to meaningfully reflect on the experiences of the participants. Hence, the researcher’s familiarity with stroke during young adulthood was beneficial to this research.

In this study the researcher found that the importance of support and a positive attitude are critical factors in recovery after stroke. It was therefore recommended that interventions focussing on emotional, physical and psychological support be undertaken, as they are likely to make significant strides during the recovery journey for not only the stroke survivor but also for their families and caregivers.

The rationale of this study was guided by the limited research of studies from a qualitative perspective, specifically focusing on experiences, as found by Murray & Harrison (2004). Further motivation to conduct this study was to address the lack of awareness of stroke in young adults, and to challenge the common misconception that stroke is a condition associated only with the elderly.

1.3 BACKGROUND

Stroke in young adults, although previously rare, has become an increasingly interesting topic to be studied due to the rising stroke rates in individuals falling within the younger age groups. Stone (2005) found that participants held the belief that stroke was a disease often associated with the elderly. Generally, it is believed that younger adults have better chances of survival post-stroke; however, the majority of these survivors have emotional, social or physical sequelae that impair their quality of life (Nedeltchev et al., 2005).

According to Bevan et al. (1990) The National Survey of Stroke in the United States of America indicated that 3.7% of strokes had been experienced by individuals falling in the young adult age category of 18 to 45 years. In her study, Lawrence (2010) explained that the mean age of stroke patients was 75 years in Western countries, with 4650 young adults experiencing stroke annually in the UK. The age category selected for Lawrence's (2010) research fell within the 18 to 45 year range.

In a study conducted in Ferrara, Italy, by Groppo et al. (2012), it was found that 39 individuals aged between 15 and 44 years, living within the study area, were admitted to hospital following first-time-ever strokes. According to the scholars, this incidence rate is fairly high as stroke is believed to be associated with older persons. They go on to explain that stroke in young adults requires more thorough diagnostic workup and specialized diagnostic testing. These results were further correlated with studies conducted in other western countries, and similar values corroborated these findings.

Kristensen et al. (1997) emphasised that candidates suitable for their studies who were considered young adults were those between the ages of 18 and 44 years old. According to the Heart and Stroke Foundation, stroke is the third leading cause of death and among the leading causes of disability in South Africa. Every hour eleven people in South Africa experience stroke (www.heartfoundation.co.za/what-stroke). Statistics in South Africa indicated that approximately 270 strokes occur daily, with premature deaths caused by strokes in people of working age (35-64 years) and a 41% increase is expected between 2000 and 2030 (Steyn, 2007). Of the 270 strokes recorded daily, at least 10 percent are expected to be amongst individuals between the ages of 18 and 45 years.

The age group of interest for this study is between 18-45 years old, as studies above recommend further investigation of stroke experience amongst young adults. Also, statistics provided by Steyn (2007) and Kristensen et al. (1997) suggest there may be an increase of stroke experience with this age group. From a developmental perspective, Erik Erikson's theory of psychosocial development states that "young adulthood" is experienced between the ages of 18 and 40 years. He argues the basic conflict at this stage is Intimacy versus Isolation, with the important event being relationships. At this stage an exploration of the personal relationships is undertaken. Within this stage it is important for young adults to form intimate, loving relationships with others. Successfully negotiating this stage will result in strong relationships, whilst failure at this stage will lead to isolation. Furthermore, Carl Jung, like Erik Erikson, postulated that adults continually develop throughout adulthood. Of his explained 4 stages, "youth" is categorized to occur from puberty until 40 years old. During this phase,

adults experience maturing sexuality, develop consciousness and realize that their carefree childhood days are no more. In this stage, young adults strive for independence, form friendships and raise families (Fleming, 2004). In accordance with Erikson and Jung's categories of adulthood, the age range will be referred to as "young adults / young adulthood" and fall between the ages of 18 and 40 years. For the purpose of this research study, similar age categories were employed, as outlined by the literature available (Bevan et al., 1990; Kristensen et al., 1997; Lawrence, 2010; Nedeltchev et al., 2005).

1.4 RESEARCH PROBLEM

The origins of the research problem relate to the fact that stroke was a previously rare occurrence among the youth (Stone, 2005) and is now fast becoming a common condition in people who fall into the young adult age category. Murray and Harrison (2004) emphasised the importance of addressing stroke as experienced by young adults, especially in providing these individuals opportunity to express themselves in the effort of lowering anxiety, after having gone through a trauma.

Researchers have found that there is a lack of awareness regarding young adult stroke survivors' experiences (Singhal et al., 2013). Hence, this study examined the lived experiences of young adults who survived a stroke to ensure increased awareness within the community.

In her own experience as a stroke survivor, the researcher observed that there was a significant gap in psychological support during her recovery process. The reason for this is not due to unavailability of resources, but rather to an oversight on the part of the treating doctors. The medical team were available to assist with physical and medicinal support; however, there was a considerable lack of providing the much needed psychological assistance to address the issues of anxiety and fear that were encountered. Murray & Harrison (2004) acknowledge this oversight when they emphasise that the psychological wellbeing of the stroke survivor is of utmost importance during the recovery phases. There is a lack of support groups for individuals who have overcome the physical constraints of stroke but are still dealing with the impact of stroke on their psychological health.

1.5 AIM

This research study aimed to explore the experiences of young adult stroke survivors.

1.6 OBJECTIVES

The objectives of this study were:

- I. To gather lived experiences from young survivors of stroke.
- II. To identify the major challenges faced by young adults post-stroke.

1.7 RESEARCH QUESTIONS

The research questions were framed according to the principals of Phenomenology, which is essentially aimed at exploring and understanding the meaning of human experience as it is lived (Wagner, 1983):

- 1) What are some of the lived experiences of young adult survivors of stroke?
- 2) What are the major challenges faced in young adults post-stroke?

1.8 RESEARCH METHODOLOGY

For the purpose of this study a qualitative approach was adopted, which allowed the researcher to gather descriptive, detailed data pertaining to the experiences of young adult stroke survivors. Furthermore, this approach permitted the discovery, exploration and entrance into the participant's world of inner experience of a phenomenon (Corbin & Strauss, 2008). Bearing this in mind, this study used an exploratory and interpretive research design. In this research study the researcher conducted Email Facilitated Qualitative Interviews (EFQI) with four participants. Interpretive Phenomenological Analysis (IPA) was used to analyse the collected data. The researcher explored and interpreted the experiences of young adult stroke survivors. Further discussion will be presented in the methodology chapter.

1.9 SAMPLING PROCEDURE

1.9.1 Recruitment of Sample and Criteria.

The sampling procedure appropriate to recruit participants was the convenient sampling technique, which allowed the researcher to carefully select participants that met the criterion for selection (Smith & Osborne, 2007; Willig, 2001).

The selecting of participants included the following criteria: Participants had to

- I. Have had a stroke;
- II. Fall within the required age category (18–40 years old) when the stroke occurred;
- III. Be able to recollect and describe their experiences of the stroke (have no impairment with regard to memory, recall or processing);

- IV. Possess the capacity to provide informed consent by acknowledging their participation in the study, and
- V. Have access to a computer, internet connectivity and email accounts.

Participants were recruited from gatekeeper organisations, namely Headway Natal, The Stroke Survivors Foundation, and Hardy and Associates, who were informed of the aforementioned criteria. Upon consenting to assist, the aforementioned organisations forwarded contact details of approximately ten prospective participants who were keen to participate in the study. Of the ten, four participants finally consented to participate in the study. A final sample size of four participants was selected. The small sample can be supported by Boyd (2001), who suggests two to ten participants are sufficient to obtain saturation in qualitative research.

Upon agreeing to participate in the study, all the relevant documentation pertaining to the focus and requirements of the study and the informed consent form were forwarded to each participant (Appendices A, D, E and F).

1.9.2 Participants' demographic information.

Below is a table that highlights the demographic information of each participant. Pseudonyms were used to protect the identity of the participants and to ensure confidentiality.

	Age (current)	Age (at time of stroke)	Gender	Race	Occupation	City of Residence	Relationship Status
Cate	23	20	F	White	Brand Manager – clothing	Durban	In a relationship
Ali	31	28	F	Indian	Social Worker	Durban	Single
Jake	26	18	M	Indian	Student	Durban	Single
Lily	41	37	F	White	Beauty Therapist	Johannes- burg	Married

Table 1

The information provided in Table 1 is a summary of the participants' demographics details.

1.9.3 Data collection process.

1.9.3.1 Email Facilitated Qualitative Interviews (EFQI).

Once the informed consent form was signed and returned to the researcher, the interview schedule was sent to each of the participants and was returned within seven days. Making use of a semi-structured EFQI schedule aimed at providing participants the opportunity to reflect on the interview questions in relation to their experiences, and to provide a descriptive, comprehensive written account of their experiences of stroke as a young adult (Egan, Chenoweth & McAuliffe, 2006). In order to combat potential geographical limitations that would have influenced the data collection in this research study, EFQI was determined as a suitable method to provide “inclusiveness that is not possible ‘in the flesh’” as explained by Cook (2011, p.1336).

This method of data collection is cost-effective, which afforded accessibility of young survivors nationwide. Upon receipt of the responses, the researcher read through the responses, cleaned the data and telephoned each participant to verify their responses to each question.

1.9.3.2 Follow-up telephonic interview.

The researcher conducted approximately one hour-long telephonic interviews with each of the participants. These interviews were arranged by convenience of each of the participants. The aim of this interview was to supplement the data that had been received, which afforded further exploration of meaning.

1.9.4 Data Analysis.

The researcher telephoned the participants to clarify all responses received, which ensured accurate interpretation. Thereafter, common themes were determined. Interpretative Phenomenological Analysis (IPA) was used to analyse the collected data. IPA is the in-depth exploration of how research participants make sense of their personal and social worlds. The focus of IPA studies is the meaning particular experiences or events hold for the participants (Smith & Osborn, 2007). Given the research objectives, IPA was a suitable selection of data analysis as it focused on the experiences of young stroke survivors.

The following steps by Smith and Osborn (2007) guided the analysis process:

- I. Looking for themes
- II. Connecting the themes
- III. Continuing the analysis with other cases

IV. Writing up

Through the process of analysis, the following themes emerged: the initial response of shock and surprise, dependency on others due to limited abilities, perceived fear of judgment, the significant role of family support, and stroke as a journey of transformative learning.

1.10 THEORETICAL FRAMEWORK

Phenomenology was selected as the most appropriate theoretical framework for this study. Within the framework of phenomenology, the focus lies on how an individual experiences a phenomenon, through exploration and reflection of personal experiences as it is lived Corbin & Strauss (2008). It allows the researcher the opportunity to gain a greater understanding of the participants' experiences; hence, from a phenomenological perspective, the lived experiences of young adult stroke survivors were explored. In unlocking the meaning derived from the experiences of the participants, the theories of reflexivity and positionality were utilised to supplement the phenomenological approach. According to Thorn (2000) phenomenology can adopt differing approaches of inquiry; however, they all represent strategies that promote immersion of oneself in data and engaging with the data reflectively.

Given her positionality in the context of this research topic, the researcher, as a stroke survivor, was able to understand contextually what was described by the participants. Phenomenology allowed for the reflective exploration of these experiences as data was being produced. Further extrapolation of the researcher's positionality and reflection will be presented in the methodology chapter. The data generated thereafter was interpretively analysed.

1.11 STRUCTURE OF THE REPORT

This research study comprises five chapters as described below:

Chapter One: Introduction and Background

This chapter provides an introduction to the research study, including the context within which the study was conducted. The research aim, objectives, questions and rationale for the study were also provided in this chapter. Research methodology and the theoretical framework of the research study are also presented.

Chapter Two: Literature Review

An in-depth review of the existing literature is provided in this chapter. The focus on non-visible and cognitive consequences of stroke, emotional challenges post-stroke, the experiences of dependency and the importance of support in the form of relational partner, family and friends are included.

The literature review highlights acknowledgement of changes to the self post-stroke, and provides a brief overview of the medical services received. It also provides insight about re-integration and adjustment into work life after stroke. Lastly the prevalence of stroke in South Africa and the facilities available to treat and manage stroke are discussed.

Chapter Three: Research Methodology

Chapter Three includes the research methodology, sampling frame, data collection methods, and data analysis for this research study. Limitations and the suitability of the methodology for the study are also highlighted. Ethical considerations, and the validity of the study are discussed in this chapter.

Chapter Four: Data Analysis and Discussion

This chapter presents the data analysis and discussion of the findings.

Chapter Five: Conclusions

Chapter five provides the conclusions from the findings of this research study, together with recommendations that may guide future research.

1.12 CONCLUSION

This introductory chapter to the research study highlighted the main aim, objectives, research questions, rationale for the research study and the context of the research problem. Additionally, the research methodology and Phenomenological theoretical framework were introduced. The chapter to follow comprises of a review of the literature of the research study.

CHAPTER TWO: LITERATURE REVIEW

2.1 INTRODUCTION

Given the nature of the proposed study, the emphasis of the literature reviewed was predominantly qualitative studies that explored the lived experiences of young adults who had experienced a stroke. These studies yielded several sub-categories, which are presented in this chapter, including the invisible and cognitive consequences of stroke, emotional challenges, the experience of dependency, the importance of support, recognition of changes to the self post-stroke, re-integration into work life and medical services received.

2.2 EXPERIENCES

2.2.1 Frustration from invisible disability.

According to Stone (2005, p.294), more often stroke survivors are left with “invisible disabilities such as cognitive difficulties, constant fatigue, and/or one-sided weakness. These disabilities are no less problematic than those that are more visible to casual observers, and in some ways, they may be even more problematic.”

Literature highlighted the experience of non-visible and cognitive consequences of stroke, as reported by several authors (Lawrence, 2010; Martinsen, Kirkevold & Sveen, 2012; Murray & Harrison, 2004; Róding, Lindstrom, Malm & Ohman, 2003). Lawrence (2010) reviewed four studies that focused on the experiences of young adults who had survived a stroke. These research papers were analysed using a qualitative assessment, which revealed that although many effects of stroke remain “invisible” (p.241), significant impact is made on their participation in and enjoyment of social activities, contributing to an active social life and their ability to return to work.

Similarly, Murray & Harrison (2004, p.814) assert that the “unseen” emotional changes as a result of stroke were more disabling than some of the physical limitations experienced by their research participants. The “unseen” disabilities were invisible to others, leading to a lack of general awareness.

The notion of “invisible disability” (Martinsen *et al.*, 2012, p.1; Róding *et al.*, 2003, p.868; Stone, 2005, p.294), proves to be relatively common amongst young adult stroke survivors. These studies elucidate “invisible disability” as subtle problems, including cognitive difficulties, persistent fatigue and/or one-sided weakness. It can be understood that through these invisible disabilities, many stroke survivors endure lowered self-esteem and difficulty expressing these concerns, as such consequences of stroke were not directly visible

and evident to others. Lawrence (2010) also found that following a stroke, many young adults felt psychologically and emotionally different, which impacted significantly on their interpersonal relationships. They felt misunderstood because of an absence of a physical disability. Lawrence's study further noted that survivors experienced frustrations when having to explain to family that although they may physically appear to have regained their health, they were confronted psychologically with difficulty to reconcile and comprehend the stroke encounter.

Martinsen *et al.* (2012, p.1) also alluded to factors such as memory and concentration difficulties and fatigue. Their participants described that these were not only frustrating to them as stroke survivors but to their families as well. Lawrence & Kinn's (2012) findings also concluded that fatigue, memory and concentration complications were evident with their participants.

Keppel & Crowe (2000) further acknowledge physical disability as a consequence of a stroke, with survivors experiencing a broad range of higher cognitive deficits and impaired social functioning. Furthermore, they add that whilst some survivors presented with deficits that were virtually undetectable (Dunne, Weedman & Edis, 1986 as cited in Keppel & Crowe, 2000), others encountered sudden physical and cognitive impairment. Additionally, they found that the slow recovery process frequently resulted in emotional and psychological distress, which was met with frustration.

In their reviews of several studies, Eilertsen, Ormstad & Kirkevold (2012) established that post-stroke fatigue was a common experience among stroke survivors. Being a dysfunction that is not directly observable to others posed a challenge to actually understand and empathise with the post-stroke survivor. The post-stroke participants in the study remarked that they would have preferred a disability that was directly visible to ensure better understanding by significant others in their lives. "The struggle in explaining fatigue might be related to the invisibility of the dysfunction, and also increased the challenges resulting from the invisibility" (2012, p.519). The participants noted misinterpretation of constant tiredness and fatigue as mere complaints. "The invisible handicap was considered to be less legitimate than other forms of handicap, and induced an obvious fear of what other people would think when they were always tired" (Róding *et al.*, 2003, as cited in Eilertsen *et al.*, 2012, p.519).

2.2.2 Post-stroke changes to the survivor and other's perception of the self.

Any illness has the potential to change and transform an individual, as noted by Murray & Harrison's (2004) stroke survivors study. Similarly, Martinsen *et al.* (2012) argue that the loss of the previously known self can significantly influence the young stroke survivor's emotional and social functioning. The loss of functioning and behaving as previously known to the survivor and to significant others often leads to confusion and difficulty adjusting to the newer self, post-stroke. The newer self is perceived as being impaired, has to deal with emotional challenges and functional changes, such as learning to negotiate around daily tasks like bathing, walking and talking.

One of the emotional difficulties experienced by stroke survivors often entailed inappropriate emotional or social responses or anti-social behaviours (Murray & Harrison, 2004). These emotions and behaviours could be as a result of possible cognitive impairment. For example, an individual might have been friendly and enthusiastic prior to the stroke; however, post-stroke they may exhibit aggression and intolerance.

Burton (2000) recommends post-stroke participants should focus on positive aspects of their lives. Likewise, Hillsdon, Kersten & Kirk (2013) described that a stroke motivated participants to prioritise their health care. Due to minor deficits, the participants in this study demonstrated the ability to care for themselves, as compared to those stroke survivors who had to experience more comprehensive physical rehabilitation. In both studies by Hillsdon *et al.* (2013) & Róding *et al.* (2003) participants compared themselves with others affected more severely by stroke, and considered themselves to be fortunate that they did not have long-term side-effects, such as paralysis.

Róding *et al.* (2003) reported that participants communicated gratitude for having survived the stroke with limited impairment and therefore should not complain about the subsequent difficulties they encountered. Participants who were parents remarked on the change of roles they encountered. Some participants communicated feelings of being emasculated or weakened by having their children witness their vulnerability, whilst others conveyed feelings of blessing to be afforded another chance to spend time with their children.

Kuluski, Dow, Locock, Lyons & Lasserson (2014) participants also expressed gratitude for being given a "‘second chance’ or told themselves that it ‘could have been worse’" (p.8). Stroke survivors in Lawrence & Kinn's (2012) study noted life altering attitudes, which offered development of new insights and awareness to cope with recovery. Burton (2000) suggested actual adjustment to physical activities was of value to stroke survivors, to believe that full recovery was possible with time and rehabilitation.

The participants expressed the inability to forget their stroke, as it played a significant role in evaluating and transforming their lives. Similarly, Róding *et al.* (2003, p.869) participants viewed stroke as having “affected them in one way or the other”, causing them to “revalue their lives; allowing for a new orientation to take place”. One of the participants in Lawrence and Kinn’s (2012) study commented on the positive influence of his stroke experience. Survivors often expressed personal, positive change as a result of the stroke, leading to self-awareness and self-growth. Stone (2005) therefore suggests further information that considers the survivor’s psychosocial aspects of recovery.

These experiences also extend to the career and work environment when considering reintegration to maintain financial independence.

2.2.3 Supportive environment.

2.2.3.1 *Familial relationships and friendships.*

Kuluski *et al.* (2014) acknowledged the importance family, friends and peer support groups had on young adults’ recovery processes. The theme referred to as ‘changed relationships’ in Jones & Morris (2012, p. 276) found that in some families tensions arose within familial relationships, as parents provided care for their stroke survivor children and this was mainly caused by disagreements in care, high frustration levels and lowered tolerance levels. On the contrary, in some familial relationships improvement in relationships were observed, characterised by increased contact, open communication and help being easily accepted. These factors created a positive change in the family system. These positive changes were subsequently well-received with the stroke survivors, who explained their experiences of stroke as bringing them closer together with their families. Hillsdon *et al.* (2013) found that most participants felt unconditionally grateful and appreciative of family assistance; however, some reported feeling stifled by their loved ones when undertaking daily tasks. Family members rallied around the stroke survivors, keen to assist wherever possible, and at times this made the survivor feel incapable and invalid.

Due to limited functional abilities, young adult stroke survivors reported that friendships and social relationships were occasionally challenging to maintain. They perceived that it was a lot of physical work and effort on the part of their existing circle of friends (Mudzi, Stewart, & Musenge, 2013) and this in turn caused stroke survivors’ friends to disengage with them. Mudzi *et al.* (2013) submitted that if the stroke survivors were more functional, their friends would have found it much easier to spend time with them.

Kuluski et al. (2014) established that stroke survivors thrived on the support from their friends and colleagues to aid their recovery, while others reported that they felt as though friends did not completely appreciate their newly found limitations as a result of the stroke, hence them distancing themselves from their social group.

Interestingly, Martinsen et al. (2012, p.7) noted that the support offered from family and friends “gradually decreased and changed”. As time progressed within the recovery phase, participants perceived their family and friends to be less available and more absent. The attributed factors noted by stroke survivors were irritability, frustrations, short-temperedness and memory difficulties, which further alienated them. Although this theme is argued as an ‘experience’ of stroke, there is interconnectedness, as it could also be construed as a challenge of stroke, as discussed above, where support can be overbearing or absent.

2.2.3.2 Partner support versus a lack thereof.

Participants in Murray & Harrison’s (2004) study felt that their apparent evident disability in the aftermath of the stroke was a deterrent in them finding romantic partners. They cited the use of walking aides or walking with a limp as an influential factor in their inability to find romance. The post-stroke participants narrated this experience, as compared to those who had already been in relationships at the time of the stroke.

The researchers further argue that those who were already in relationships at the time of their stroke were fortunate and could dedicate themselves fully to their recovery, with the benefit of having a partner to support them. In contrast, a negligible number of participants described how the stroke had negatively impacted on their intimate relationships with existing partners, some of which lead to the dissolution of the relationship or divorce.

2.3 PSYCHOSOCIAL CHALLENGES

2.3.1 Emotional challenges.

In their study, Hillsdon et al. (2013) found that several participants initially experienced shock and disbelief, as it was assumed that stroke occurs only within the elderly, and was uncommon among the young.

Murray & Harrison (2004) also indicate that whilst there are a variety of rehabilitation facilities to offer stroke survivors the opportunity to re-learn tasks and become as independent as possible post-stroke, the non-visible impairments of stroke are often left unattended to. They noted emotions of fear, anxiety, grief and frustration following their stroke experience. In addition, they suggest that these psychological limitations often

prevented stroke survivors from carrying out their daily activities. Moreover, the diminished self-confidence as a result of the physical difficulties was distressful for participants. The participants in the study also faced emotional challenges post-stroke, such as becoming overly emotional, easily tearful and frequently overreacting to ordinary stressors. These emotions evidently impact on their self-esteem and confidence.

Stroke survivors believed that observable disabilities would elicit more empathy and understanding from significant others. The study by Róding *et al.* (2003) reports similar findings, where survivors preferred a physical disability so that family members were more likely to understand the reason why they were unable to undertake certain tasks. They elaborated on a visible disability, such as a paralysed arm or leg, as opposed to a non-visible disability such as weakness or fatigue. Some of the observable disabilities could be misconstrued as the individual being inebriated or tipsy, and the emotional response to such a misinterpretation is of shock, surprise, anger and frustration. They oftentimes need to explain to others about their circumstances (Murray & Harrison, 2004). Róding *et al.* (2003) also noted that although an observable disability would have been preferred, it is the misinterpretation of the observable reactions that has influenced the emotional wellbeing of their participants.

Sympathy was another essential factor emphasized by Martinsen *et al.* (2012). They also noted the perceived over exaggeration of symptoms by family, friends and caregivers. Therefore, there was a need to defend their symptoms, as these were not visible, but were rather cognitive complaints or physical weakness.

Keppel & Crowe (2000) identified depression as prominent, especially in the immediate recovery phase, amongst stroke survivors as they negotiate around post-stroke circumstances, which often are challenging to meet. The depressive state may cause significant impairment on the quality of life of young adult stroke survivors. Some identified impairments were social withdrawal, feelings of helplessness and hopelessness and loss of independence.

2.3.2 The challenge of dependency.

Beyond the emotional challenges experienced are the loss of previously known self, dependency, control and self-efficacy (Martinsen *et al.* 2012). Some participants reported difficulty in shifting their roles within their family units. It should be noted that participants construed dependency as a challenge, due to the consequences of dependency, hence it is

discussed in this section. They explained that moving from being the caretaker to the one needing to be taken care of was difficult to adjust to.

Burton (2000) also shared the concept of loss and noted that loss of control associated with the aftermath of stroke, both in physical and social activities of life, provoked a strong sense of frustration in study informants. This linkage between control and frustration appeared to be most strongly related to the physical effects of stroke.

In Burton's (2000) study it was explained that survivors experienced short tempers, memory difficulties and concentration problems. Their loss of independence to meet daily chores and staying home to recover made them feel like invalids, worsening their feelings of vulnerability. Their depressive symptoms in the recovery phase were attributed to negotiating dependency for their basic needs. In addition, Kuluski et al. (2014) established additional challenges in their study, such as eating and bathing. These scholars summarised that the "shock of diagnosis, the initial symptoms, and the impact on day-to-day functioning (which was once second nature to them) were met with much frustration" (p.4).

Jones & Morris (2012) conducted interviews with young adult stroke survivors and offered four themes that emanated, namely emotional turmoil, significance of parents, negotiating independence versus dependence and changed relationships. Their theme of 'independence versus dependence' (2012, p.277) support the findings of Burton (2000) and Kuluski et al. (2014) that stroke survivors experience feelings of guilt and disappointment for being dependent on caregivers.

The participants in Jones & Morris' (2012) study declared a sense of incongruence of having regressed into requiring their parents to care for them during the post-stroke phase. They were confronted with feelings of shame at needing their parents' assistance. They felt "positioned in a dependent role that was a regressive step and echoed their experience of childhood" (2012, p.276). Similarly, Kuluski et al. (2014, p.4) shared the experience of reverting to childhood, as if they were "a baby with an adult mind". They recommend the importance of accepting and adapting to dependency during the recovery process.

In addition, Jones & Morris (2012) found that participants had the urge to retain some of their privacy so as to avoid feelings of vulnerability post-stroke. Their participants noted some difficulty in their relationships with the parental caregivers, as the young adults were often held back in a careful and guarded manner creating tension between them. The reasons provided for the resistance included the need to retain a certain amount of independence and to avoid feelings of worthlessness. Martinsen et al. (2012) also found that when stroke survivors felt that their disability created interactional challenges in their relationships with

others, they resorted to withdrawing and attempting to be independent, which frequently made them feel socially isolated. On the contrary, some stroke survivors withdrew to preserve their independence, and this resulted in tension and anxiety between them and their significant others.

2.3.3 Factors associated with re-integration.

Lawrence's (2010) analysis noted participants experiencing difficulty reintegrating into their pre-stroke lifestyle, such as returning to work, as they were often unable to cope with the demands of their job post-stroke. Kuluski et al. (2014) found that participants felt that to return to one's work life was seen as an accomplishment and an integral part of the recovery process. This was appreciated even if the job they were returning to differed to the one they had pre-stroke.

Often, for the duration of their recovery and recuperation, survivors experience additional financial stressors, possibly losing their jobs (Stone, 2005). An additional argument presented by Stone (2005) is that unmet needs of young stroke survivors, including assistance with their finances, intellectual stimulation and the need to return to work, continues to be unaddressed.

Another salient factor of stress is mentioned by Róding et al. (2003), who highlighted a lack of age-appropriate rehabilitation as being a source of great frustration for young adult stroke survivors. These researchers assert that due to tiredness, irritability, anxiety and memory difficulties, few young stroke survivors return to work within one year of the incident, despite minimal or no present physical impairment. In seeking treatment for these impairments, stroke survivors reported varied encounters. Accordingly, their participants recommended that rehabilitation programs should include age-appropriate information.

2.4 STROKE IN SOUTH AFRICA

2.4.1 Incidences of stroke in South Africa.

According to the report published by the Heart and Stroke Foundation in 2013 (www.heartfoundation.co.za/physical-activity) at least 80 percent of deaths among the youth in South Africa could have been avoided, had a more healthy lifestyle been followed. Stroke is the second most common cause of death in young adult South Africans after HIV/AIDS-related deaths.

In addition, Pongvarin (2007) and Bryer et al. (2010) argue that the incidences and burden of stroke on the community are alarmingly high in South Africa. Connor et al. (2008,

p. 8) cite Yusuf, Reddy, Ounpuu & Anand (2001), Bonita (2001) and Cappuccio's (2004) argument that stroke is likely to increase in Sub-Saharan Africa (SSA) "as the population ages and undergoes epidemiological transition". At least half of the stroke burden in South Africa is borne onto 'mostly rural' parts of the country (Maredza et al, 2015, p.9). These researchers indicated that approximately 95000 years lived with disability in South Africans is due to stroke. They highlight that published studies on epidemiology of stroke in rural South Africa is lacking.

2.4.2 Treatment and management of stroke in South Africa.

Generally, patients who present with stroke are treated by neurologists and cardiologists, depending on the site of the stroke. However, in South Africa very few neurologists are specialists in stroke (Fritz, 2006). These doctors treat stroke patients; however, they have limited, if any, access to stroke facilities for formal stroke rehabilitation. In South Africa, most patients are treated by a multidisciplinary team, who often are not experts on stroke treatment and recovery (Fritz, 2006).

As a result of the high prevalence of HIV/AIDS, Bryer et al. (2010, p.755) assert that management in young South African stroke patients is further complicated. "HIV infection may cause stroke through opportunistic infections, secondary to involvement of the heart by HIV, possibly by changes in coagulation factors, and through direct or indirect damage to blood vessels" (HIV associated vasculopathy).

Furthermore, Bryer et al. (2010) suggest that services provided to stroke survivors should be categorised so as to meet unique requirements of specific groups, such as young adult patients or paediatric patients. These services should be customised appropriately to suit the various cultural, literacy and linguistic diversity of South Africa. Patients who present with stroke during young adulthood are likely to be referred to specialist stroke units, as they often present with unknown causes for the stroke.

2.4.3 Stroke facilities in South Africa.

Fritz alluded to financial constraints being the reason for "very limited government support for stroke care" (2006, p.47). She adds that certain academic hospitals have chronic and acute stroke facilities and also refer out to specialist stroke rehabilitation clinics. She added that, in South Africa, existing stroke units are accessible to only approximately 10–20% of the population. In addition to this, Maredza et al. (2015) highlighted that the much-

needed dedicated stroke units within the South African public health system is limited even though stroke incidence is on the rise.

Progressive findings by Bryer *et al.* (2010) indicate that stroke units are now present in former African townships in Cape Town and Johannesburg. In addition to these, several privately run rehabilitation facilities specialising in stroke are in existence across South Africa. It is clear from abovementioned information that a difference is present in the academic hospitals and the state supported facilities.

“The current high fatal burden warrants urgent measures for stroke interventions in South Africa” (Maredza *et al.*, 2015, p.10). Given the absence of government initiated interventions, the burden of stroke in rural South Africa appears to be of epidemic proportion. These scholars indicate that these interventions are likely to prevent several disability-causing strokes.

Despite numerous media attempts to raise awareness of stroke cause, care and rehabilitation, knowledge of these is still remarkably poor amongst the general public. Fritz (2006) argues that current South African Government research, medical and financial interest is aimed at HIV/AIDS, which is justifiable given the current epidemic. However, given that the stroke incidence is on the increase, government and medical awareness should also focus on increasing ease of access to stroke units for stroke patients, so as to limit the burden of stroke in South Africa as far as possible.

2.5 PERTINENT GLOBAL STUDIES ON THE MANAGEMENT OF STROKE IN YOUNG ADULTS

These studies highlight the dominant and integral role of the doctor-patient relationship during recovery and rehabilitation of stroke survivors. Hillsdon *et al.* (2013) reflected on such a relationship, where several of their participants cited self-research to advance their knowledge of stroke, as their treating doctors provided limited information. The researchers argue that appropriate pertinent knowledge would benefit families in understanding the psychological and emotional challenges experienced by the stroke survivor. In addition, knowledge of the appropriate assistance and rehabilitation processes will be beneficial to both family members and the stroke survivor.

Róding *et al.* (2003) found some participants expressed disappointment with regard to their doctors, who had not been more forthcoming about the “disease and prognosis in the early stages of stroke” (p.870). It was perceived that doctors did not provide adequate knowledge and information about their stroke, which is also supported by Hillsdon *et al.*

(2013). Having said this, there were opposing views expressed by participants in relation to doctor-patient relationship. Some participants would have appreciated doctors' firm instructions, clear guidelines and management on post-stroke care. On the other hand, other participants held that doctors were too prescriptive and dictated protocols without considering their unique situation, which lead to feelings of vulnerability and invisibility. It was felt that their contribution to their own treatment plan was overlooked (Hillsdon et al., 2013; Roding et al., 2003).

2.6 CONCLUSION

This chapter concentrated primarily on qualitative studies of young stroke survivors. The literature reviewed highlighted studies with opposing views and experiences of young adult stroke survivors during their post-stroke rehabilitation and recuperation phase. Factors that were discussed included emotional and psychological challenges, concerns about re-entry into the workplace, doctor-patient relationship and, briefly, the South African challenges and perspectives. The following chapter will provide the discussion on research methodology and the theoretical framework employed in this research study.

CHAPTER THREE: RESEARCH METHODOLOGY AND THEORETICAL FRAMEWORK

3.1 INTRODUCTION

This chapter focuses on the research methodology applied to the study. Although introduced in Chapter One, this chapter elaborates on the research process being cognizant of the objectives of the study. An outline of the sampling method, a brief description of each of the four participants, data collection and the analysis method will be presented. The theoretical framework adopted for the study will be discussed in-depth to demonstrate understanding of the theory and concepts in relation to the research topic. The chapter concludes with the ethical considerations and limitations of the study.

3.2 RESEARCH DESIGN

This research study was essentially qualitative in nature, as the researcher was interested in gathering descriptive, detailed data pertaining to the experiences of young adult stroke survivors. The study used an exploratory and interpretive research design.

According to Gray (2009, p.35) exploratory studies “seek to explore what is happening and to ask questions about it”, especially when sufficient information is not known pertaining to a phenomenon. Within the context of this study, an explorative approach affords the interpretation of lived experiences of young adult stroke survivors. Since the focus of the study had been established, as Gray (2009) stated, interpretive research is then possible. The nature of interpretive studies is to “explore people’s experiences and their views on these experiences” (2009, p.36). Interpretive studies are inductive and are linked to qualitative research.

The qualitative approach enabled this study to discover, explore and enter the participants’ world of inner experience of a phenomenon (Corbin & Strauss, 2008).

According to Nwoye (2013), in qualitative research methodology the study involves the descriptions of *first-person* experiences or the notion of *life as it is lived*. This study also utilizes phenomenology, as the focus of the research question lies in making meaning of the lived experience of young stroke survivors (Burke, 2004).

In qualitative research, the researcher shares in the understandings and perceptions of others and explores how they structure and give meaning to their daily lives. This was pertinent to the study, since without consideration to context and skills to connect with

participants, it would prove challenging to get an insider perspective to meet the stated objectives of the study.

3.3 SAMPLING PROCEDURE

3.3.1 Recruitment of sample.

D'Cruz & Jones (2014) maintain that non-probability sampling does not aim to produce findings that can be generalized through statistical analysis and there is no claim of generalization of results. They suggest a connection between the sample size, aim and purpose of the research.

The sampling procedure appropriate to recruit participants was the convenient sampling technique, which allowed the researcher to carefully select participants that met the criterion for the selection (Smith & Osborn, 2007; Willig, 2001). Convenient sampling is described as a non-probability strategy that uses the most conveniently accessible people to participate in the study (Gray, 2009, p.575).

Gatekeeper organisations, namely Headway Natal, The Stroke Survivors Foundation, and Hardy and Associates, were informed of the sampling criteria in order to recommend suitable participants. These Gatekeeper organisations are National bodies, therefore recruitment extended nationally. Upon consenting to assist and once ethical clearance was obtained, the Gatekeeper organisations contacted suitable participants who fulfilled the criteria, informing them of the proposed study and enquiring in their keenness to participate. Subsequently, those individuals who were keen to participate granted the gatekeeper organisations the permission to forward their contact details to the researcher. The potential participants were currently employed in the workforce at various organisations and/or were studying at various tertiary institutions across South Africa, further indicating that they did not experience severe cognitive impairment as a result of the stroke. This was essential, as cognitive functioning of participants was a key component in order for them to have the capacity to provide informed consent.

Approximately ten prospective participants were keen to participate in the study. This was communicated to the researcher, who thereafter telephoned them. All relevant research details including the focus of the research and the requirements of participation were discussed with the participants. Of the ten, four participants finally consented to participate. A final sample size of four was selected. Three out of the four participants lived within the greater Durban areas and one participant was from Johannesburg. All relevant documentation highlighting the research purpose, requirements of participation and informed consent forms

were subsequently emailed to them (Appendices D, E and F). The Informed Consent form outlined the purpose of this study, procedure, risk and benefits of participation that participation was voluntary, that they were free to leave the study at any point, and that information provided will be confidential and their identities will be protected (Groenewald, 2004). Once the informed consent form was signed and emailed to the researcher, the interview schedule was emailed to the participant (Appendix A).

The small sample size can be supported by Boyd (2001), who suggests two to ten participants are sufficient to obtain saturation in qualitative research. Saturation implies that no new information is obtained from the interviews. IPA studies generally have small samples because the detailed analysis of response is time-consuming. Also, it allows for a comprehensive explanation regarding the understandings and experiences of young adult stroke survivors rather than general claims (Smith & Osborn, 2007).

3.3.2 Sampling criteria.

The Gatekeeper organisations were informed of the following set of criteria and were asked to select potential participants based on these. The selection of participants included the following criterion:

- I. Have had a stroke;
- II. Fall within the required age category (18–40 years old) when the stroke occurred;
- III. Be able to recollect and describe their experiences of the stroke (have no impairment with regard to memory, recall or processing);
- IV. Possess the capacity to provide informed consent by acknowledging their participation in the study, and
- V. Have access to a computer, internet connectivity and email accounts.

3.3.3 Description of sample.

Pseudonyms are used in the description of the sample to protect the identity of the participants. Kendall (2008) states that providing a brief description of participants' histories is essential in understanding the context in which the participants' experiences were formed.

Cate, a 23-year-old female, experienced her stroke at the age of 20. It had been three and a half years since her stroke and she has continued working since her recovery. The post-stroke consequence has been slightly weaker muscle tone on her right hand. In order to improve her muscle tone and right arm, Cate attends sessions with an Occupational Therapist

and Physiotherapist. Her stroke experience negatively impacted her romantic relationship at the time, and the relationship has subsequently ended. Cate's new partner was described as being supportive and patient.

Ali is a 31-year-old female. At the time of her stroke she was 28 years old and employed full time. It had been three years since her stroke and she currently works part-time as she is still in recovery. She experiences difficulty with her left arm, which remains bent at the elbow, and attends sessions with an Occupational Therapist to help improve movement in her limbs. Her experience of stroke has made her reliant on family members to carry out her daily hygiene rituals. She was single at the time of her stroke and is currently not involved in a romantic relationship.

Jake is a 26-year-old male who experienced a stroke at the age of 18. It had been six years since his stroke. He was a scholar at the time and encountered significant difficulties upon returning to school post-stroke. The lobes responsible for his Mathematics and Science abilities were affected. Jake has made considerable progress; however, he experiences some difficulty with his memory, retention and concentration, for which he receives cognitive rehabilitation. Jake is currently not in a relationship, and was single at the time of his stroke.

Lily is a 41-year-old female who was 37 years old and employed full-time when she had her stroke. It had been four years since her stroke and Lily has just obtained part-time work. As a result of the stroke she lost significant muscle function in her left arm. She attends sessions with Occupational Therapists and Physiotherapists. At the time of her stroke, Lily was married with three children. Her husband has been supportive and helpful throughout her recovery.

3.4 DATA COLLECTION PROCESS

Once the research instrument was sent to the four participants, their responses were received after seven days. The researcher then read through each of the received responses and cleaned the data. Each written response averaged four A4 pages. The researcher conducted a follow up telephonic interview at the participants' convenience, which lasted approximately one hour each. During this follow up telephonic interview, the participants were firstly thanked for their participation, thereafter the researcher went through their responses question by question. This allowed for the clarification of their written word and for further exploration, which added to the comprehensiveness of the data.

3.4.1 Research instrument: email facilitated qualitative interviews (EFQI).

Benford & Standen (2011) assert that the internet has the ability to reduce the physical and geographical barriers for people who are socially marginalised and promote their participation in research. Furthermore, the internet provides a medium through which these individuals can have their voices and stories heard. McAuliffe (2003), as cited in Brondani, MacEntee & O'Connor (2011), associated interviewing through the electronic medium more suited to the youth than those of old age. Making use of a semi-structured EFQI aimed at providing participants the opportunity to reflect on the interview questions in relation to their experiences, and to provide a descriptive, comprehensive written account of their experiences of stroke as a young adult (Egan *et al.*, 2006).

Brondani *et al.* (2011, p.226) emphasise that email provides a “context for a non-coercive and anti-hierarchical dialogue to promote equal opportunity and reciprocity, which constitutes an ideal situation free of internal or external intimidation” (Creswell, 2007, as cited in Brondani *et al.*, 2011). As evident in the literature review, several young adult stroke survivors felt misunderstood and judged, as they had invisible consequences resulting from their strokes, making EFQI an effective data collection method of choice.

When Cook (2011) was preparing to conduct her study on how the diagnosis of a herpes simplex virus (HSV) or human papilloma virus (HPV) impacted the lives of women, she set out to use traditional face-to-face interviewing. However, she soon changed her data collection method after learning that email interviewing was fast becoming popular and a preferred method when conducting research with individuals who were “vulnerable or marginalised” by health diagnoses (p.1331). She offers that for the duration of her research she had learned how email interviewing was suitable for health science-related research studies (McCoyd & Kerson, 2006 as cited in Cook, 2011).

Should the researcher have opted to use face-to-face interviews, the participants may not have felt comfortable enough to disclose their experiences (Egan *et al.*, 2006). EFQI allows a greater sense of privacy and security, which enables open, freer discussion of sensitive topics (McCoyd & Kerson, 2011). It is elaborated that anonymity is highly possible during EFQI as visual cues are absent and may enhance the participants' confidence in self-disclosing (Egan *et al.*, 2006; McCoyd & Kerson, 2011). They elaborated that due to the absence of visual cues, participants with noticeable defects or disabilities (in this research study, resulting from the stroke) would have their contributions treated in the same manner as all other participants.

In addition, Cook (2011, p.1336) states that email interviews provide “inclusiveness that is not possible ‘in the flesh’”. As stated above, geographical limitations would have influenced the data collection for the study. Hunt & McHale (2007) and Meho (2006) describe the email interviewing approach as valuable, since it overcomes interviewer effects. Face-to-face interviews are often influenced by the personal visual observations of the interviewer or the participant. Therefore, conducting interviews via email in this study avoided such interviewer effects. This method of data collection was also cost-effective and afforded accessing several young adults who were stroke survivors nationally.

Bampton & Cowton (2002) argue using email interviews as a data collection technique is an asynchronous and in-depth approach, which is valuable, since the data provided by participants was not shared, viewed or influenced by other participants. Hence, in this research study, participants provided their individual experiences of stroke as young adults.

Moreover, the suitability for email interviewing was appropriate for this study, as Egan *et al.* (2006) highlights that it is a tool that is well-suited to deal with sensitive areas of inquiry. McCoyd & Kerson (2011) argue that the utilisation of EFQI is versatile, as participants are able to construct their responses at their leisure. This involves working at their individual paces, either completing the interview schedule all at once or question-by-question, as well as selecting an environment in which they feel safe and comfortable to provide their responses.

Egan *et al.* 's (2006) methods to assist a researcher using EFQI were adopted by the researcher as follows:

- a) Re-reading the texts assisted the researcher to familiarize herself with the wording and discourse.
- b) Once the written text was re-read, a follow-up telephonic interview, lasting approximately one hour, was conducted with each of the participants. This allowed the researcher to clarify and obtain a better understanding of the written word, and for further exploration of the meanings, prior to embarking on the analysis process.

McCoyd & Kerson (2011) emphasise that data collected through EFQI is deemed credible, as participants provided answers in a conscious and mindful manner, which provides enriched, detailed data. Participants included a description of emotions and thoughts, which can be empowering for them. In this way, the process of self-reflection and personal description increased the credibility and trustworthiness of the information.

Oftentimes, interviews that are conducted telephonically take place when the participant is at home or work, where colleagues or family members are likely to overhear their responses, which could contribute to their reluctance to disclose their truest opinions and feelings. Therefore, this study afforded participants the opportunity to respond to interview questions without the fear of being overheard McCoyd & Kerson (2011).

In summary, these are some of the benefits of EFQI as proposed by McCoyd & Kerson (2011, p.396) which have been discussed above:

- Respondents are provided the opportunity to construct their responses at their leisure;
- Responses are text-written, therefore negating the need for transcription.

Some disadvantages of email interviews have been reported by scholars. Technological challenges including the disappearance of text, difficulty accessing email addresses (Meho, 2006) and the inability to observe emotions directly (McCoyd & Kerson, 2011). Reliance on technology, which sometimes proves to be difficult to navigate, further poses a shortcoming in email interviewing. Aware of these shortcomings, the researcher obtained landline telephone numbers, mobile numbers and an alternate email address for each of the participants.

Upon receipt of each of the responses, the researcher conducted a follow-up telephonic interview with each of the four participants.

3.4.2 Follow-up telephonic interview.

According to Gray (2009), telephonic interviews are widely used, as they are a quick and efficient way to gather data while being cost-effective. Telephonic interviews in phenomenological studies afford for further exploration of meaning. The purpose of the telephonic interview was to supplement the data that had been received and to extrapolate more meaning. In doing so, the researcher was also able to clarify the responses provided by the participants.

The follow-up telephonic interview was administered once the responses had been received and read by the researcher. A time that was convenient for each of the participants was arranged in order to carry out the interview. Each interview lasted approximately one hour long, as the researcher went through each response step-by-step with each of the participants.

The use of multiple methods to gather data, namely EFQI and the follow-up telephonic interview, subscribes to the true traditional phenomenological paradigm, which suggests that multiple methods of data gathering should be employed (Gray, 2009).

3.5 INTERPRETIVE PHENOMENOLOGICAL ANALYSIS (IPA) AS A METHOD OF DATA ANALYSIS

The focus point of Interpretative Phenomenological Analysis (IPA) is the in-depth exploration of how research participants make sense of their experiences and world (Smith & Osborn, 2007).

IPA is not a prescriptive methodology, but mere guidelines to carry out the analysis process. For the purpose of this study, Smith & Osborn's (2007) method of analysis was adopted to explore the young adults' understandings of stroke, as context and meanings are critical to experience. Smith and Osborn (2007, p.54) described the "word 'understanding' emphasizing two aspects of interpretation:

- (1) understanding in the sense of identifying or empathizing with and
- (2) understanding as trying to make sense of something".

IPA looks at the connection between what is being said and that of the emotional and mental state of the participants. In addition, it considers the cognitive and mental processes involved in self-disclosure.

The analysis process commenced when the researcher telephoned the participants to acknowledge their responses. During the call, the researcher clarified all responses received by each of the participants to ensure interpretation and accuracy when reading through each of their responses.

The Analysis Process was guided by Smith & Osborn's (2007) four stages, which appear as follows:

Step One: Looking For Themes

Responses are to be read and reread several times for the researcher to familiarize him/herself with the content, as expected within IPA. The left hand margin was used to note interesting and significant responses. The purpose of re-reading the data has the potential to highlight new insights. This process allowed the researcher to summarize, paraphrase and link initial interpretations across participants' responses. In addition, similarities, differences and contradictions expressed by participants were highlighted.

The initial notes are transformed into the emerging themes. These themes are noted in the right hand margin. The richness of the data is reflected by the number of themes generated.

The researcher printed hard copies of the responses for analysis and back up. The researcher followed the guidelines, as stipulated above by Smith & Osborn (2007). Through the reading and re-reading of the responses, annotations were written on the left hand side (Appendix H). This was an important step for the researcher to familiarize herself with the comments and meanings expressed by the participants. Attempts were made to paraphrase, make connections and to provide preliminary interpretations. The initial notes were then documented as comprehensive themes that captured the essential meaning found in the text. The purpose of these comprehensive themes may bring to mind psychological concepts. The process above shows the transformation of initial notes into emerging themes.

Step Two: Connecting the Themes

According to Smith & Osborn (2007), the emerging themes are listed chronologically and connections between these themes are made. Once these connections are made the next step involves the theoretical ordering of the themes. Similar themes will be clustered together while others will emerge as superordinate concepts. The clustering of themes was checked against the actual accounts of the participants in their responses to ensure the clustering of themes made sense.

The next stage required the researcher to tabulate the themes logically and orderly. The table of themes outlined the participants' concerns, as per the research question and topic. The clusters of themes were given names in order to represent the superordinate themes. Identifiers were added to indicate where in the data the original source may be located (Smith & Osborn, 2007). The "identifier indicates where in the transcript instances of each theme can be found by giving key words from the particular extract plus the page number of the transcript" (p.72).

The guiding principles outlined above were followed by the researcher, where clusters of themes were cross-referenced with the responses to ensure appropriate summarization. Themes that emerged from the responses during analysis were not predetermined. See Appendix M entitled Clustering and Naming of Themes for a detailed outline of the process. The process of clustering and naming themes was selected as evidence to answer the research questions:

- i. What are some of the lived experiences of young adult survivors of stroke?

- ii. What are the major challenges faced in young adults post-stroke?

Step Three: Continuing the Analysis with other Cases

Smith & Osborn (2007) outline two possible options that characterize this step. Option 1 entails using the list of emerging theme titles from the first analysed responses to inform the analysis of the remaining data. Option 2 suggests that each response is analysed independently, and treated as though it was the first to be analysed.

The researcher followed Step 1 and Step 2 with the three remaining responses. For the purpose of this study, Option 1 was selected by the researcher. The table of themes from the analysis of the first response was used as a guideline during the analysis process for the remainder of the data. It was carefully observed to take note of new emerging themes that had not been generated from the first response. When this occurred, the researcher reviewed previous responses to ensure that data substantiating the new emerging themes had not been overlooked. These new themes were then added to the table of emerging themes. Upon analysis of all four responses, a master table of themes was created. The researcher then prioritized the data according to the research question and reduced them in order to conclude which of the themes should be focused on (Appendices L and M).

Step 4: Writing Up

The final step in analysis includes moving from the master themes to the writing up of the meanings, derived from the participants' experiences. Once new insights are no longer being generated, in that the process has become exhaustive, the analysis process draws to a close. The researcher must translate the themes into a narrative account, explain each theme and substantiate it with direct quotes from the participants' responses. Smith and Osborne (2007) assert that meaning is not made by simply reading through the collected data; rather, it has to be acquired by constant interaction with the text, accompanied by a process of interpretation. There are two ways in which the findings may be presented: 1) The emergent themes are explained and a separate chapter is dedicated to the discussion that is supported by existing literature; and 2) Each theme and its association to existing literature is explained in one chapter (p.76).

Once the analysis process was concluded, the researcher wrote explanations for each of the themes and provided the direct quotes that supported each theme. Through this process the researcher attempted to understand the meaning of the experiences, as expressed by the participants. For this study, the researcher presented the findings and discussion in relation to the existing literature together in a single chapter, as outlined by the second option above.

3.6 ETHICAL CONSIDERATIONS

Ethical considerations have been considered when conducting this research. The researcher ensured the study was guided by ethical principles as follows:

3.6.1 Informed consent.

In order to provide informed consent, participants need to be cognitively capable to understand and make an informed decision regarding their participation. For this research, participants were required to have the cognitive capacity to recall their experiences, which translated to them having the capabilities to make an informed decision. In this study, all four participants were required to sign a written informed consent form. This form included information regarding the purpose of the study, its objective and the method in which data will be collected. The informed consent form also stipulated the risks and benefits involved in participation and that their participation is voluntary. They were informed that they may withdraw without consequence at any time.

3.6.2 Privacy.

Participants were informed that data collected will be shared with the supervising researcher and the university community without identifying details being disclosed. Furthermore, they were informed that this research was intended for a Master's Thesis and that findings may be disseminated through publication. The participants raised no objections regarding this.

3.6.3 Anonymity and confidentiality.

During data collection, personal email accounts that were password-protected were used for both the researcher and participants, ensuring confidentiality. Anonymity in this research had implications of not disclosing identifying details of participants in the write up of the Thesis. The researcher made use of pseudonyms when formulating the report write up, which assured confidentiality.

3.6.4 Harm to respondents.

The informed consent form stipulated that, should participants become distressed during the participation process, they may contact the researcher for a de-briefing session. McCoyd & Kerson (2011) advise that in research surrounding mental health, researchers should equip themselves to recommend mental health follow-ups, should a participant

become distressed during the research process as a result of participation. They go on to stipulate that these “comparable protection” measures should be put into place (2011, p.395). They asserted that it is mandatory that researchers explore, inquire about and attend to emotional distress the participants may feel. The onus is upon the researcher to make certain that ample referral sources for mental health support are made available. These scholars further explain that an ethical researcher is armed with lists of mental health professionals, and participants are informed as to where they may access the appropriate help if necessary, should they become distressed during the research process.

In order to comply with the ethical considerations as suggested by McCoyd & Kerson (2011), the researcher equipped herself with details of help-lines, privately practicing psychologists, as well as trauma counsellors in close proximity to the participants’ homes, in the event of participants becoming distressed during this study. This was done once the participants had agreed to take part in the study and their geographical positions were known to the researcher.

The researcher telephoned the participants once their responses had been received. If participants had expressed their distress to the researcher, or if the researcher suspected the participant had become distressed as a result of participation, the researcher planned to provide the participant with telephonic counselling or de-briefing. If further intervention was required, the telephone numbers mentioned above would have been made available to them.

From a qualitative perspective, there is a need to protect and take responsibility of human beings as participants of a study. According to Townsend, Cox & Li (2010, p.618), qualitative research allows for “respect for autonomy, beneficence and non-maleficence, which has become a key component of any discussion of the researcher-researched relationship, ensuring that the end objective in qualitative research does not override the rights, health, wellbeing and care of research participants.” In this study the researcher remained focused on the wellbeing of the participants throughout the process of participation and follow-up by constantly checking in with participants to determine if they had become distressed as a result of participation.

3.7 THEORETICAL FRAMEWORK: PHENOMENOLOGY

Phenomenology from the Greek *phenomenon* means to show itself (Groenewald, 2004). A Phenomenological framework was selected as the most appropriate theoretical framework, as it allowed young adults to describe their stroke encounters and for

comprehensive meaning of their lived experiences to be unlocked (Ricoeur, 1976, as cited in Martinsen et al., 2012; Moron, 2000; Willig 2001).

Husserl (as cited in Moron, 2000) states that phenomenology entails a careful description of things as they appear to the consciousness. Essentially, it explores the meaning of human experience, as it is lived individually, by delving into the personal world of the participant to unlock the meanings of those experiences (Nwoye, 2013). Smith (2003) also supported that phenomenological research provides the opportunity for description of perceptions, cognitions, beliefs, recollections, observations, representations, contexts, emotions and judgments of participants' lived experiences.

According to Welman and Kruger (1999, p.189), "phenomenologists are concerned with understanding social and psychological phenomena from the perspectives of the people involved" (as cited in Groenewald, 2004). Bentz & Shapiro's (1998, p.96) explanation that at the root of phenomenology, "the intent is to understand the phenomena in their own terms – to provide a description of human experience as it is experienced by the person herself" and allowing the essence to emerge (as cited in Groenewald, 2004).

In phenomenological research, emphasis is placed on exploring and discovering what people with common experiences encounter. Data is collected in the form of understanding participants' lived experiences of that encounter, followed by the researcher developing understandings of the meanings made by participants' experiences. In this way, people that share a common encounter are brought together to participate in a study; however, meaning is derived from their individual experiences.

In remaining true to the phenomenology tradition, the researcher explored reflectively the depth and detail of the lived experiences of the participants. In unlocking the meaning derived from the experiences of the participants, the theories of reflexivity and positionality were utilised to supplement the phenomenological framework. Phenomenology generates a rich description that will "enlighten a reader as to the deeper essential structures underlying a particular human experience" (p.69). Gray (2009, p.23) asserts the following about phenomenology:

"Far from using a theoretical model that imposes an external logic on a phenomenon, this inductive approach seeks to find the internal logic of the subject."

The following table is an adaptation from Gray (2009, p.23), who adapted it from Easterby-Smith et al. (2002).

Basic Beliefs	The world is subjective and is socially constructed. The observer is party to that which is being observed. Science is driven by human interests.
The researcher should	Focus on meanings. Attempt to understand what is happening. Use an inductive approach.
Methods include	Using multiple methods to establish views of a phenomenon. Use of small sample sizes to conduct in-depth research. Use of qualitative methods.

Table 2

This research study remained true to the phenomenological paradigm by consistently following the methods as described in Table 2.

BASIC BELIEFS

Gray (2009) highlights that the tradition of phenomenology incorporates that the world of the participant is constructed socially and is of their subjective experience. Within this research, subjectivity comes from the sample frame, therefore from the participants themselves. The data is a construction of their real world and their encountered experiences. The participants are observers of their worlds and their subjective experiences. Through analysis, meanings are unpacked by quoting direct narratives of the participants. Moreover, the research question, “What are the lived experiences of young adult stroke survivors?” is being addressed, as the research extrapolates the meaning participants attach to their own lives.

This research was driven by the researcher’s peaked interest in this research topic. As lives make up various roles, researchers need to be cognizant of how their life experiences shape the type of research they conduct and how they analyse their research. The researcher’s positionality as a stroke survivor afforded her reflection throughout the study as both an insider and outsider. Herod (1999) argues that in order to obtain the truest knowledge, research should ideally be carried out by the ‘insider’ as opposed to the ‘outsider’, as the latter carries significantly more cultural differences that will need to be stripped away. Understanding that the interview process is influenced by both the interviewer and the interviewee, interviewers hailing from different cultural or social backgrounds may shape the

process in different ways. Given her positionality in the context of this research topic, the researcher, as a stroke survivor, was able to understand contextually what was described by the participants.

THE RESEARCHER SHOULD

Within the phenomenological paradigm, this study unpacked the lived experiences of what occurred post-stroke for each of the four participants. The written narratives provided by each of the participants emanated different meanings and themes. The researcher aimed to understand the meanings made by each of the participants. Meaning was attached from each interview and each narrative. The researcher inferred meanings from the narratives and constructed the emerging themes, therefore using an inductive approach.

Reflexivity is having an awareness of the role of the researcher within the research, its process and the findings of the research. Additionally, being reflexive entails being aware that the researcher and the phenomenon being explored are likely to influence not only each other, but the research process as well (Alvesson & Skoldburg, 2000). These scholars highlight (2000, p.481) that researcher reflexivity involves “thinking about how our thinking came to be, how pre-existing understanding is constantly revised in the light of new understandings, and how this in turn affects our research.”

Reflexivity necessitates thinking about our experiences and questioning our ways of doing (Hibbert, Coupland & MacIntosh, 2010). During reflection, the researcher shifts focus onto himself or herself, the research population and their traditions that may influence the research. Interpreting the interpretation from the research is what makes the research reflexive (Hibbert *et al.*, 2010). Reflexivity is not one single process, but rather an ongoing, continuous process that should be carried out at every phase of the research (Guillemin & Gilam, 2004). Hertz (1999), as cited in Guillemin & Gilam (2004), asserts that a reflexive researcher will go above and beyond reporting facts and findings to “construct interpretations” about how they came into existence (p.274). Guillemin & Gilam (2004) go on to cite Jenkins (1992), who observed Bourdieu’s thinking that reflexivity involved taking a step back to objectively observe the topic of research, followed by stepping back from the research to reflect on what was observed in the first step taken.

Guillemin & Gilam (2004, p. 275) explain that reflexivity is to reflect critically on how the researcher “constructs knowledge from the research process” and examine the types of influencing factors on the researcher’s construction of knowledge and how these influences are evident in the planning, conduct, and writing up of the research”. A reflexive

researcher is cognizant of the factors that influence his or her research and is capable of examining his or her function within the research in a critical manner. The aim of being a reflexive researcher is to enhance the validity and quality of the research.

In true qualitative tradition, constant reflection on emerging interpretations were engaged with. In being reflective throughout the research process, the researcher constantly observed her understandings of the responses provided by participants; particularly relating to rehabilitation and recovery. In doing so, the researcher made numerous comparisons of her own experiences with the information that was provided.

In using reflexivity to supplement the theoretical framework of phenomenology for this study, the researcher made note of theoretical assumptions and preconceptions about the subject of the research and revisited these throughout the research process, observing and noting if and how they may have shifted. The researcher also considered if these shifts altered the research question and objectives. A research diary noting the unfolding about the research process was maintained by the researcher. Notes documenting interaction with the participants, telephonic conversations and emotions and responses were highlighted throughout the research process (Appendix O). Whilst examining the emailed responses, the researcher noted how the presence of the data or her interaction with it as a researcher affected the process of analysis. All these notes and observations were continually discussed with the research supervisor. Phenomenology allowed for the reflective exploration of these experiences as data was being produced. The data generated was thereafter interpretively analysed.

METHODS INCLUDE

The researcher used EFQI to obtain written narratives from each of the four participants. Furthermore, she conducted follow-up telephonic interviews with each of the participants. This afforded further elaboration and depth of understanding of the data in order to extrapolate more meaning. The small sample size of four is further evidence that the study abided to the true traditional methods of phenomenology, which allows for in-depth research to take place. Given that the study is essentially qualitative in nature, it further substantiates the selection of a phenomenological framework.

3.8 VALIDITY

Nwoye (2013) cites Maxwell (2001), who indicated that in qualitative studies it is more appropriate to talk of trustworthiness and credibility of the research. As described in the

literature review, EFQI allowed the participants the ability to consciously reflect upon their answers and provide detailed responses. Participants were selected according to specific criteria and were asked to explore their own experiences. Therefore, the data that was collected from participants was their true explorations of their experiences of stroke as young adults. Given that this is their truth, it further lends dependability and trustworthiness to the data collected.

3.8.1 Credibility.

Maxwell (2001) as cited by Nwoye (2013, p.11) asserts that credibility and trustworthiness can be enhanced by making a copy of the text of the report available to the study participants to “cross-check if it accurately portrayed their perspectives regarding the phenomenon investigated”. This was done in the form of the telephonic follow-up between the researcher and the participants, as described above. The purpose of the follow-up interview was to obtain clarity of the responses provided, and to further elaborate on the meaning thereof. Respondent validation was ensured through the researcher’s follow-up telephonic interview. Ensuring respondent validity lends credibility to the study. McCoyd & Kerson (2006) found that the richness of the data provided by participants compared favourably with face-to-face interviews, indicating that data gathered using the EFQI technique is credible.

Wolcott (2010, as cited in Nwoye, 2013) stated that, in qualitative studies, readers have the right to know the research, know the researcher, his or her personal gains from the research study and their affiliations to the phenomena being explored. Hence, the researcher used a reflexive approach, a further characteristic of qualitative studies, to supplement the theoretical framework, in order to provide an in-depth analysis. This further enhances the credibility and trustworthiness of this study.

Feedback was provided to participants to validate the researcher’s understanding and to support the descriptive interpretation of the responses, increasing dependability and truthfulness.

McCoyd & Kerson (2006) found that the richness of the data provided by participants compared favourably with face-to-face interviews, indicating that data gathered using the EFQI technique is credible.

3.8.2 Dependability.

As this study was conducted in accordance with a Master’s Degree, all research procedures and changes thereof were documented in detail. The purpose of this is to ensure

that the study could be monitored or supervised at any given time by the research supervisor or another significant party.

3.8.3 Confirmability.

All raw data such as written notes, data reduction and analysis, data reconstruction notes, process notes and the proposal will be stored for a period of five years. After this period, all recordings will be deleted and hard copies destroyed by the use of a paper shredder.

3.8.4 Transferability.

By providing deep and detailed accounts of the interviews, the conclusions were drawn and could be utilised in other similar studies, thus contributing to the existing literature on this area of research.

3.9 LIMITATIONS OF THE STUDY

The following limitations are noted:

- Although a reflective approach was declared, the researcher's own experiences as a stroke survivor may have inadvertently influenced the manner in which the data was received, analyzed and interpreted. To obviate any misinterpretation of the narratives, the researcher conducted follow-up telephonic interviews with the participants to ensure accurate reflection of their written narratives, prior to commencing with the data analysis.
- The sample was drawn from three National Gatekeeper organisations, namely Stroke Survivors Foundation, Hardy and Associates and Headway Natal. The sample does not represent all individuals and may exclude adult stroke survivors who have restricted access to such organisations.
- The small sample size of four participants did limit the generalizations of the results. The small sample can be supported by Boyd's (2001) notion that suggests two to ten participants are sufficient to obtain saturation in qualitative research.
- Although the study did not deliberately accommodate for equity of gender, of the four stroke survivors who consented to participate, only one was male. This translates to the results not being generalizable to the entire population.

- Location was not controlled, during recruitment of the sample and, inadvertently, three of the participants who ultimately consented to participate in the study were residents of Durban and one of Johannesburg,
- Finally, the subjectivity of the lived experiences of the four stroke survivors are acknowledged in the study and cannot be viewed as universal themes common among all young adult stroke survivors in South Africa.

3.10 CONCLUSION

In this chapter the qualitative nature of the study was validated and the researcher presented the sampling method used in the study, as well as brief descriptions of each of the four participants. The data instrument used and the method of analysis were discussed. The theoretical framework was presented with motivating factors for its suitability to this research study. This chapter also highlighted the ethical considerations of the study. In order to contextualise the findings, the limitations of the research study were presented. Data analysis and the discussion of findings will be presented in the chapter to follow.

CHAPTER FOUR: DATA ANALYSIS AND DISCUSSION

4.1 INTRODUCTION

This chapter details the research findings of the study. Through the process of IPA, themes and subthemes were identified. The researcher aimed to provide the interpretations of the participants' worlds and the underlying meanings, as suggested by Gray (2009). These meanings afforded relevant themes and subthemes to emanate as they related to the research questions of the study. The direct narratives of the participants are italicised and indented. Pseudonyms are used to protect participants' identities.

4.2 EMERGING THEMES

As mentioned above, the following themes and subthemes were analysed through the lens of the research questions proposed by this study, namely:

- What are some of the experiences of young adult stroke survivors?
- What are some of the challenges young adult stroke survivors face?

The themes are as follows.

It became increasingly evident that although these themes are presented separately, they remain interconnected as both challenges and experiences of the participants.

1. The Initial Response of Shock and Surprise
 - 1.1. Appropriate response by medical practitioners
2. Frustration Due to Limitations
 - 2.1 Dependency on others due to limitations
 - 2.2 Frustration as a result of dependency
 - 2.3 Frustration at slow progress
 - 2.4 Post-stroke frustrations within the intimate relationship
 - 2.5 Temporary loss of independence
3. Perceived Fear of Judgment
 - 3.1. Being judged on physical restrictions
 - 3.2. Being judged on restrictive cognitive capabilities
4. The Significant Role of Family Support
5. Stroke as a Journey of Transformative Learning

4.3 THEME 1: THE INITIAL RESPONSE OF SHOCK AND SURPRISE

This theme summarises participants' expressions of shock and surprise when initially informed of their diagnosis. Three of the four participants explained the reasons for their shock or surprise, which was primarily due to their perceived belief that stroke generally associated with the elderly and is uncommon in the young, as Cate mentioned:

"It was a shock to me. I went in for something else, came out with a stroke."

Ali added:

"It was a big shock for me. Strokes are common in old people. I've never heard of anyone young having a stroke... I went blank; I didn't believe at that moment that something was wrong with me. I thought that if I could walk, how could I have had a stroke if I can walk and my legs are moving?"

Lily commented:

"I thought my colleague [who had identified her symptoms as being those of a stroke] was mistaken because I was far too young to be having a stroke and was talking normally."

In true phenomenological tradition, these participants gave meaning to being shocked and surprised when initially diagnosed with stroke. Seemingly, their similar understanding was that stroke generally presents in older persons and, given that they were young adults at the time, their response to being told that they had had a stroke was shock, surprise or even disbelief. This diagnosis can be interpreted as being unexpected due to their age. Ali may also have felt betrayed by her body as she did not feel indisposed prior to the diagnosis, given she was only 28 years old at the time and healthy. This theme is supported by Hillsdon et al. (2013) and Stone (2005), whose studies also found that their participants expressed initial shock and disbelief at the time of their strokes, since they believed that stroke was an illness that presented in late adulthood. Ali's graphic description of "going blank" could be likened to intense shock and possibly feeling numb, which could be common when facing exceptionally shocking, unexpected news. Moreover, the absence of 'stroke symptoms' may have intensified the feeling of shock and possibly lead to disbelief. This could be interpreted as the absence of symptoms may cause doubt in the diagnosis as there are no tangible symptoms being encountered. Being a social worker, Ali could have been aware of the

common symptoms of stroke, and it is likely that she assumed the first symptom to arise would be one of paralysis. The absence of paralysis in her presentation may have caused Ali the disbelief she experienced. Ali felt that because she was able to walk, her symptoms were not a representation of stroke. For Lily, her ability to speak normally can be interpreted as her understanding that stroke first presents with speech deficits or the inability to speak, and as a result of her ability to communicate normally, her diagnosis was met with disbelief. Therefore, her ability to talk normally was indicative to her that she was indeed healthy. It can be understood that Ali and Lily hold similar meanings that one ought to have a presence of some symptom of a stroke; however, they differ in that for Ali it was physical movement and for Lily it was cognitive ability such as speech.

In Cate's experience, she explained having sought medical help for not feeling well. However, upon hearing the stroke diagnosis, her response was one of shock and astonishment. This suggests that even though she may have been feeling unwell, she did not consider the symptoms to be related to a stroke.

It can be suggested that a challenge for young adult stroke survivors may be the acceptance of the initial diagnosis, as they assumed that in their youth it could not be possible to experience a stroke. The reason for this could be attributed to their conceptions that strokes are presented generally in older age.

4.3.1 Subtheme 1.1: Appropriate response by medical practitioners.

Once the initial response and surprise of their diagnosis had been established, young adult stroke survivors reflected on the medical services they had received when seeking treatment at the time of their stroke. Two out of the four participants described negative encounters when seeking medical assistance at the time of their stroke. Delays in treatment, not having sufficient medical tests administered and being turned away from doctors contributed to these participants' unique unpleasant experiences, since it is generally assumed that the medical doctors possess the appropriate expertise.

Ali shared her disillusionment:

"I felt disappointed that my condition was not assessed quickly. At the hospital they took their time to treat me – they treated me as how they treat older stroke patients.... they should have acted faster – so I would have minimal limitations now.... I have a concurrent diagnosis of Lupus – which means extended recovery time from the stroke. I could have been diagnosed from the beginning... the doctor gave me birth control pills – without testing my blood. If they knew about the lupus they wouldn't have given

me the birth control pills. Then I wouldn't have had the stroke. I am angry with that doctor, for his negligence."

Ali expressed her discontent and anger at not having her condition treated with the urgency that it warranted. It appears as though her expectations of receiving prompt, efficient treatment was not met and this was likely to contribute to her anger toward the service received. Moreover, it appears that her pre-existing medical condition of having lupus was not considered, which was directly linked to her experiencing a stroke. Clearly, her anger was exacerbated by not being treated for her unique pre-existing diagnosis, where a proper medical history would have obviated. Being a social worker, Ali is aware of the importance of documenting the history of a presenting case, as it has implications for diagnosis and appropriate treatment and intervention.

Lily cites her negative encounter:

"The hospital sent me home and told me I was attention seeking. I got to the hospital within 30 minutes of symptoms arising. Then we went to our personal doctor who sent us back to hospital to the physician. They conducted MRI and drug tested me and discharged me. I couldn't walk but they told me to go home."

Lily expresses that even though she sought medical assistance swiftly after her symptoms began, she was viewed as "attention seeking" and finally sought medical treatment from her family doctor.

It was apparent that both Lily and Ali felt they promptly sought medical attention but they were met with inefficiency and incompetence by the medical staff. For Lily, the poor diagnostic abilities and the lack of knowledge were evident among the hospital staff. For Lily there was a complete absence of medical treatment offered, as she was turned away despite having attended a privately run hospital. As noted by Lily, the private hospital she attended was ill-equipped and uninformed in their treatment and management of stroke in young adults. Had these shortcomings been adequately addressed, it can be assumed that the repercussions of Lily's stroke would have been less severe. Being accused of attention-seeking successively undermines her lived experience. Moreover, enduring a drug test suggests a demoralizing experience. Aside from pathology and radiology investigations, the lack of a simple assessment of her overt inability to walk is indicative of inefficient diagnostic and treatment abilities by the medical staff. It can be assumed that the time lost contributed to the severity of the stroke for both Lily and Ali. Ali declares the consequences

of stroke could have been minimised, had the appropriate prompt assistance been afforded. Lily's inadvertent time wastage between the hospital and her private doctor has significant meaning for her, in that her limitations as a result of the stroke may have been diminished or avoided had she initially received efficient treatment. Although their respective encounters vary, both attach meaning to the inefficient service received, or in Lily's case, not received.

Lily and Ali's sentiments of their poor reception at their respective hospitals suggest that young adults face challenges when they present to medical professionals. Róding *et al.* (2003) also found that participants of their study were unhappy with their treating doctors; however, their reasons were based on doctors not being "forthcoming about the disease and prognosis in early stages of stroke" (p.870). According to www.mystroke.co.za/stroke-units, South Africa's response time to stroke is on average four hours. This means that the average time from onset of stroke to first response treatment received is on average four hours, as compared to Sweden's 20 minute average. This is according to acute stroke care expert Dr Nikolaos Kostulas, head physician for the department of Neurology at Karolinska University Hospital, Sweden (as cited on www.mystroke.co.za). The reason for this is due to poor knowledge of stroke presentation and, as a result, the general public takes longer in reporting to hospitals and clinics. It is vital to understand that once four and a half hours have lapsed since the onset of an ischemic stroke, medication to resolve the blood clot cannot be administered as the risks outweigh the benefits after the so-called 'golden hour'. Both Lily and Ali's mismanagement highlight the lack of awareness and knowledge on stroke treatment in some private medical facilities South Africa. However, privately run hospitals are increasing their capacity to address this essential service by developing dedicated stroke units and rehabilitation facilities (www.mystroke.co.za/stroke-units, www.ehhe.co.za, www.lifehealthcare.co.za). However, there continues to be a strong absence of similar stroke units within the Public Health system, with the exception of Groote Schuur Hospital in the Western Cape and Inkosi Albert Luthuli Central hospital in KwaZulu Natal (www.mystroke.co.za/stroke-units).

4.4 THEME 2: FRUSTRATION DUE TO LIMITATIONS

All four participants described feeling frustrated due to various difficulties or challenges they faced post stroke. This included physical limitations and partial abilities; the reliance on others for assistance to carry out tasks and meet needs that they were previously able to execute, and a perceived lack of understanding of their new found circumstances by others. It was observed that all four participants cited the word "frustration" to describe how

they felt when encountering these obstacles. The following sections are divided into four: namely, frustration due to limitations; reliance on others; slow progress and perceived lack of understanding by others, post-stroke.

Very early post-stroke, young adult survivors describe having to navigate their new-found unique limitations. Participants expressed that these restrictions were a substantial source of their frustrations. They expressed frustration at feeling confined and being unable to be independent and care for themselves. Being able to mentally process and envision what it is like to walk or move an arm, then not being able to carry out the required movement resulted in frustration.

Lily narrates her irritation:

"I was frustrated a lot...throw something to get the frustration out...I needed assistance with everything I wanted to do – it was very very frustrating."

Lily expresses her frustration at requiring assistance from those around her for most of her tasks and facilitated her anger by flinging things around. The extent of her frustration appeared to be rooted in the level of dependency she had on others. It can be assumed that because Lily was a previously employed, financially independent capable wife and mother, her adjustment to her new recent found limitation and dependency on others are linked to her heightened frustrations.

Similarly, Cate confirmed:

"....I couldn't walk, talk or swallow. I could not sit up on my own, and needed help to get seated on my bum. They would make me sit up and I would fall over. I was worried I would never walk again and it was frustrating not being able to do these simple things for myself like I could do before."

For Cate, the essence of her frustration appears to be in executing the tasks she was no longer able to successfully undertake. Acquiring the ability to remain seated is a seemingly unthought-of task. It is only when this ability is diminished or taken away that acute awareness of its significance becomes evident. Cate's expressions suggest her overwhelming concern of being unable to walk and talk again, as mentioned in Theme One. This experience can be construed as terrifying and debilitating during the recovery process, as much self-motivation is required to navigate through these difficult stages.

Jake's frustration was caused by being immobile and his inability to move freely as he did before:

"Initially it was just overcoming the frustration of being confined to a wheelchair and having to lie in bed all day."

Being an 18 year old young man, confined to a wheel chair and bed invariably frustrated him, as his contemporaries were preparing and planning for entrance to tertiary institutions. The meaning attached to this state of immobility caused frustrations.

This theme of feeling frustrated due to limitations is supported by Burton (2000, p.306), who states that the "loss of control...provoked a strong sense of frustration in study informants. This linkage between control and frustration appeared to be strongly related to the physical effects of stroke". The freedom of being independently mobile and negotiating such movement at will is assumed. These participants demonstrated that even the motion of sitting up required assistance, which exacerbated the feelings of frustration. Moreover, the constant comparison of before and after the stroke episode was a constant amongst the participants' reflections.

4.4.1 Subtheme 2.1: Dependency on others due to limitations.

These physical and cognitive limitations invariably meant increasing reliance and dependence on others. They were rendered weaker with impairments that necessitated assistance. These included a range of physical and cognitive difficulties that made everyday tasks such as bathing, dressing and running errands a challenge. The feeling of dependency is reinforced by the care of and interaction with significant others.

Ali articulated her dependency on her family:

"It doesn't feel good to be dependent on people. It is disempowering. It feels like I am a small baby, like they are changing my diapers. Taking a bath I have to rely on my mum to help. Changing into my underwear after a bath is still a challenge. These simple tasks make me feel inadequate at times. I felt like I was a baby. I needed people to do everything for me."

Ali describes her frustration at having to rely on her family for assistance with her basic hygiene, dressing and other menial needs. She felt disempowered at having to be so

dependent on those around her to fulfil these basic needs, those which she was able to carry out independently prior to her stroke.

Lily added:

"I felt like a child, learning to do things all over again – walking etc....If I wanted to bathe, my husband had to help. He came into the shower to make sure I didn't slip. Having to rely on someone is deflating....I needed assistance with everything I wanted to do – it was very, very frustrating. I knew exactly what I wanted and knew how to do it, but I just couldn't do it."

While Ali felt disempowered, in a similar manner, Lily expresses reliance on her husband to assist her with her basic hygiene needs, which was devaluing. She explains how it can be frustrating to know what one wants and how it can be done but being unable to undertake such a task by oneself, as before. The expression of deflation suggests diminished self-worth, self-image and self-confidence. Ali and Lily commandingly describe their experiences of reliance on others. Perhaps, being the oldest two participants, the need to be cared for at such an intimate level resonated more with them than with Jake and Cate. Lily was also a mother of three at the time of her stroke, and it appeared that her challenge of requiring help from her husband translated to her inability to provide for her children, who like her, required similar care and support. This further suggests having one's self-assurance diminished, due to the reliance of others to assist with basic self-care routines. This is also maintained by Kuluski et al. (2014), who found that common challenges expressed by participants post-stroke included difficulties in carrying out activities of daily living, such as eating and bathing. The participants' dependence also implied their susceptibility and vulnerability within their environment of care. The negative perceptions of dependency, as described by participants, indicate their reframing of the meaning to be reliant on others. They liken it to regression into an infantile stage, where they required help with these basic tasks that they had learnt in infancy. The interpretation of this significant regression in young adulthood is indicative of embarrassment and awkwardness to have simple tasks executed by others. Jones & Morris (2012, p.276) also found that stroke survivors felt "positioned in a dependent role that was a regressive step and echoed their experience of childhood." For Ali, it can be understood that obtaining daily help with putting on her underwear is representative to her of having a diaper changed. At her age it was rather uncomfortable, even embarrassing for her as it highlights extreme dependency.

Cate recounts:

"I was like a baby. I couldn't do anything. I had to learn it all..."

Cate, Ali, Lily and Jake emphasized the regression experienced, which further connoted a level of discomfort, embarrassment and possible humiliation. In support of this, Burton (2000) also established that stroke survivors felt their need for help to carry out mundane tasks, such as dressing, triggered negative reactions. As a result of her impairment, Ali described feeling a sense of helplessness. Regression was not only viewed in light of being dependent, but also in the way in which the participants had to relearn how to conduct everyday tasks. This, by implication, meant spending a substantial amount of lost time concentrating on achieving independency once again, while their contemporaries were engaged in other typical age-appropriate activities.

Although Jake did not comment on having to depend on others to assist him with everyday tasks, he expressed his chief challenge was to relearn basic movements and tasks during his time at the Rehabilitation Unit:

"....I was taught everything to do from scratch as though I was a new born baby. I felt like a new born baby having to use my arm and leg and learning the basics from virtually scratch."

Although Jake spent several weeks at a rehabilitation facility, he does not detail how these needs were met as opposed to the females in this study, who were very explicit in their explanations. Jake's experience of having to relearn how to use his limbs can be further interpreted as helplessness. Again, here the reflection of the regressive state for Jake was frustrating, as he had to revert to being taught bodily movements.

The theme of dependency on others provides authoritative insight into the lived realities of what young adult stroke survivors experience immediately following their diagnoses and during early stages of their recovery process. In true phenomenological tradition, all four participants provided individual meaning to their feelings of dependency, as they had to interact with those responsible for their care and recuperation. Further, the connotation of disempowerment and diminished self-confidence and self-worth are repeatedly interpreted from their narratives. It is also within this interactive space that the interpretive approach recognises the reality of these participants, as they relate to their primary care-givers in the recovery process (Marlow & Boone, 2011). Although these can be

construed as experiences, there is an inextricable link with challenges that they face, especially during the early phases of their recovery and rehabilitation.

4.4.2 Subtheme 2.2: Frustration as a result of dependency.

It appears the challenge of dependency often resulted in young adult stroke survivors feeling frustrated. By being unable to carry out tasks and meet rudimentary needs that they were able to previously execute, participants communicated their frustration at having to rely on those around them for assistance. This singular frustration of reliance also meant having their needs attended to at times that were suitable to their care-givers. This meant that they would be unable to carry out tasks at their leisure and had to exercise patience in order to have their needs met by others. The feeling of frustration due to dependency was reiterated by participants as a significant difficulty. Ali expressed sheer frustration with herself as she was unable to independently care for herself as she did before.

Ali explicates her frustrations of having to rely on others for assistance to meet needs:

"I couldn't drive. I felt irritated...the frustrations got me sometimes. I shouted and cried. I used to call my sister to come wash my back. She would take so long...I would get frustrated with myself because I couldn't do it for myself. I would say to her that if I could do it myself I would. Then I would scream and cry."

Ali explains that she was no longer able to wash her back as her arm had become immobile after her stroke. For Ali, this meant that she had to rely on her sister for such assistance. It appears as though this limitation and reliance on her sister contributed pointedly to Ali's frustration, which resulted in her becoming emotional. Martinsen et al. (2000) argued that feeling dependent on others adds to feelings of frustration, which supports Ali's statement above. In addition, when her sister was unable to fulfil her needs in time, it seems Ali's frustration progressively worsened, as she was unable to do what she desired. Ali's frustration is captured also as being impatient, not only with her sister but with her inability to act independently and with the pace of her recovery.

4.4.3 Subtheme 2.3: Frustration at slow progress.

As a result of experiencing stroke during young adulthood, Ali described her expectancy of recovering quickly and fully, given her age. She expresses her frustration, however, with her slow improvement:

"I felt that the recovery process was too slow. My left hand is taking quite long to progress and this is a source of my constant frustration."

As discussed earlier Ali's experience with the medical staff was unpleasant and disappointing. Here, again, being unable to regain the use of her hand contributed to further frustration. It appears as though Ali's cognitive processes are high functioning, even post-stroke, and her body was attempting to catch up, which she interpreted as slowness. Slow progress is also identified by Dunne et al. (1986, as cited in Keppel & Crowe, 2000), who cited it as the root of frustration for young adult stroke survivors, as they felt improvements should be seen quicker. Perhaps Ali's expectations of a quicker recovery would mean that she could return to her social work position, which would infer resuming a state of normality in her life. Ali was also the only participant who commented on the sluggish progress as compared to the other three participants, who did not deliberately mention the pace of recovery. The fact that she viewed the pace as a persistent frustration cannot be devalued from her peculiar circumstances and expectations.

4.4.4 Subtheme 2.4: Post-stroke frustrations within the intimate relationship.

As a result of the stroke, Cate articulated that she had to negotiate her new found limitations and reliance on others for assistance with daily activities. In the following excerpt, Cate describes her frustration as a result of her boyfriend's lack of understanding and intolerance of her post-stroke presence:

"He got irritated with me and frustrated when I couldn't do things as I did before. He would get impatient...because I couldn't use my arm properly. This frustrated me as I couldn't accept myself because he just wouldn't understand what it was like for me after the stroke".

Having her boyfriend not recognize the limitations of post-stroke bodily changes contributed substantially to Cate's frustrations. The annoyance communicated by her boyfriend not only inferred his impatience, but intolerance of her post-stroke capabilities. His lack of empathy directly influenced and increased her frustration. Empathy is defined as "the ability to understand another person's distress" (Gibson, Swartz & Sandenbergh, 2002, p.9), which clearly Cate expected from her boyfriend. It is within these intimate relationships also that a "deep level of caring for the other person is a basic component" (Corey & Corey, 2014, p.272), which Cate expected a demonstration of by her boyfriend.

The other participant in an intimate relationship, Lily, who was married at the time of her stroke, did not cite similar frustrations with her relationship with her husband.

4.4.5 Subtheme 2.5: Temporary loss of independence.

The loss of independence was experienced by two of the participants. Ali and Lily in particular expressed how their independence had been temporarily taken away from them as a result of the stroke, as they now relied on others to have their basic needs met.

Ali reported that:

"I was planning to be as independent as possible but everything has been put on hold for the moment. I had to stop working."

She explains that, as a result of her stroke, her plans to gain independence have been thwarted, as she had to stop working due to her limitations caused by the stroke. Being a social worker for five years when she had her stroke, it can be assumed that Ali was self-sufficient in providing for herself. By having her independence removed so abruptly, it forced her into a significant level of dependency. The shift from being independent and a competent social worker to the other end of the spectrum, that positioned her as requiring substantial assistance, was challenging. Having the stroke forced Ali to stop working, which contributed to her loss of independence. As a social worker, it is likely that Ali found her work self-gratifying, as many helping professionals do, but her role changed from being the helper to becoming someone who required assistance. She also noted her physical limitations that added to her loss of independence.

Similarly, Lily adds:

"Losing independence was my biggest change. Noticing how I used to be so independent and free before is a big challenge. You only realise when it's gone. It was difficult not being able to do things for myself. Even though I have difficulty with walking and my left arm, losing independence is still my biggest challenge."

Being a mother of three young children contributed to this feeling, as she was required to fulfil the needs of her children. Moreover, the financial implications of not being able to work after her stroke contributed to a sense of loss also, as she was unable to contribute substantially to the household expenses. The significant shift in her role, from provider and carer to dependency and being unable to care for others, offered insight into the

deflating feeling, as described by her earlier. It can be construed that the loss of independence was viewed as a challenge by Lily and Ali, given that they were older than Jake and Cate at the time of their respective strokes. The loss of independence could be assumed to have been more severely experienced by them than their younger counterparts. Being older suggests more responsibility and perhaps less time to focus on oneself, as the focus shifts to caring for parents who are growing older and, in Lily's case, caring for her children.

Lily, in particular, expressed her excitement at returning to work and once again gaining her financial independence:

"Now I am starting work tomorrow, so I am looking forward to being independent."

During the follow up telephonic interview, Lily shared that she had been offered a job at a beauty salon and would be starting the very next day. Her excitement and enthusiasm at this new prospect and returning to work, three years after experiencing her stroke, was obvious on the telephone. Her keenness to return to work and regain her independence is supported by Kuluski et al.'s findings, which highlight the importance of returning to work post-stroke, where one of their participants "talked about what it meant to her to get her job back, even though it was a different job than she had before her stroke" (2014, p.8). Even though Lily had obtained a different job to the one she held before, the prospect of becoming independent again and feeling as though she was making a contribution to her family was exciting for her. It can be assumed that even as Lily navigates the physical limitations of the stroke, her ability to find work and contribute to the household once again is meaningful to her existence.

As participants described having to relearn basic tasks they were previously competent at, the power of regaining their abilities to become competent once again translated into taking control of their lives. Being dependent on both physical and financial assistance left participants longing for the independence they previously enjoyed. Even with physical limitations caused as a result of the stroke, some of the participants indicated that the loss of their independence was yet the worst outcome they had experienced after their stroke.

4.5 THEME 3: PERCEIVED FEAR OF JUDGMENT

Participants conveyed concerns about being judged by others, particularly about their physical restrictions and constrained cognitive abilities.

4.5.1 Subtheme 3.1: Being judged on physical restrictions.

As a result of limited mobility, participants were unable to carry out tasks easily. Adjustment and acclimatising to these individual limitations was a foundation of frustration, as discussed in the theme above.

Cate explains her concerns about being judged due to her limited physical abilities:

"I did feel judged by my boyfriend at the time. When I couldn't do things he judged me...It made me feel like something was wrong with me."

Cate's feelings expressed earlier, about her boyfriend's lack of empathy is further exacerbated by his judgement of her inability to independently assist herself. Judgement, as noted by Hepworth, Rooney, Rooney & Strom-Gottfried (2013), can be counterproductive. For Cate, it almost places her again within a vulnerable position of interrogating her own abilities. The often taken for granted tasks may also create doubt of their own capabilities. Cate's lived experience can be interpreted as having a non-supportive partner, leaving her to confronting feelings of incompetence, which is clearly not conducive for any relationship. In addition, it can be anticipated that judgment will extend beyond the intimate environment, which can hinder the young adult's journey to recovery.

Although Ali experienced significant physical limitations, she did not report feeling judged, therefore this is unique to Cate's lived experiences of stroke as a young adult. Her experience of being judged can potentially influence her self-image, where her limitation is viewed as a consequence of her experience.

4.5.2 Subtheme 3.2: Being judged on restricted cognitive capabilities.

Stroke may cause cognitive impairment, ranging from mild to moderate and even severe. One of the four participants expressed his concern about being judged, due to his cognitive impairment as a result of his stroke.

Jake experienced minor cognitive impairment pertaining to his concentration and memory retention abilities. He feared that his educators would see him as not being a diligent student, since his established academic record was good prior to the stroke. He was anxious that despite his marks being lower, he nonetheless worked twice as hard as before to perform at an average rate. His keenness to maintain an average academic record meant a concerted effort by himself to ensure that he communicated his persistence to others around him to persevere.

Jake articulated that:

"My marks had plummeted by around 30-40% as compared to what I was scoring in them before the stroke had occurred. From the outside, it probably seemed that I had given up on studies however this was far from the truth as I feel that in actual fact, I was probably twice as dedicated to it."

Jake also expressed that he had significant difficulty in learning new concepts. This caused his marks to drop, which made him worry that his teachers would think that he was being lazy or not trying hard enough.

"I had found grasping of concepts to be significantly difficult. Where it might have taken a student an hour to learn something, it would take me two or two and half hours, sometimes more depending on how difficult the concept was."

He explained that it took him double the time it would take an average student to learn something, as the stroke had impacted his concentration and memory retention. His descriptions of his minor cognitive difficulties are supported by existing studies (Keppel & Crowe, 2000; Lawrence & Kinn, 2012; Martinsen et al., 2012). These studies emphasise memory and concentration difficulties as some of the non-visible consequences of stroke. Jake was the only participant who commented on difficulties with cognition after their stroke, possibly because he was still a student, while the other three were employed and no longer studying at the time of their strokes. Jake also included another dimension, namely that of motivation as a result of being judged, by increasing his efforts in his scholastic performance.

4.6 THEME 4: THE SIGNIFICANT ROLE OF FAMILY SUPPORT

All four participants communicated their overwhelming gratitude to their family for supporting them during their stroke and the recovery process. The support as described by participants included emotional support and physical support.

As Cate maintained:

"I had emotional support...My parents were by my side throughout. Mom was there every minute. She laughed with me and let me cry when I needed to. She held me when I needed to cry. My mom was my rock. Love from my family motivated me to get better. Without them I would never had the strength to fight the way I did."

Cate expressed how her family allowed her to safely convey and display her emotions, and that their continued support sustained her positivity during her recovery

process. She also acknowledged her extended family and friends who offered emotional support to her family, which contributed to her strength during her recuperation. Despite her boyfriend's perceived lack of understanding and his judgment of her, it appears Cate's family's support was a huge asset in her healing. It can be assumed that the emotional support offered from her family afforded Cate the safe space she needed to adjust post-stroke, and to engage in some of the difficult processes during rehabilitation. Similarly, Ali also expressed her appreciation for her family's support, particularly focussing on their physical support. Ali noted:

"You can't make it without family support. Besides physical support, they were patient and understanding. They didn't harp on the things they helped me with."

It appears she felt supported by her family, not only through their physical assistance, but also in their keenness to continuously help her with her physical limitations. Although earlier she described her frustrations of reliance on her sister and her feelings of helplessness above, it seems she is undoubtedly indebted for their constant, unselfish and guiltless assistance. Even though she referred to her dependence as disempowering, Ali appears to not feel the need to reciprocate the help or assistance she received because they did not remind her of the help and support they offered her.

"It doesn't feel good to be dependent on people. It is disempowering."

"Besides physical support, they were patient and understanding. Didn't harp on the things they helped me with, they just did it without asking for anything."

This can be inferred as the true meaning of assistance post-stroke; where all efforts are made with no reciprocity required. Given this safe, supportive environment created by her family, as well as the absence of fear of being judged or not being understood, it is apparent that Ali was dedicated and focussed on her recovery. This is further evidenced by her comments earlier of expecting to recover quickly. Seemingly, Ali was afforded the space to channel all her energy and focus on her recovery. Similarly, Jake shared that his mother's knowledge of stroke and outcomes of stroke helped him to prepare for what lay ahead for him. He added that having people around him, continuously encouraging him to be patient, to pray and to remain positive, are necessary contributory factors towards his recovery process.

Jake articulated that:

"She would often explain to me exactly how I was affected. She would continuously stress to me the importance of patience, a positive mind-set, determination and most importantly, prayer. I was extremely blessed to have a strong support structure. Beginning with family and friends and extending to teachers and even outsidersalways ready to offer me assistance."

The impact that Jake's mother had on his recovery was pivotal in facilitating the process. Her patience and positivity and prayer clearly were acknowledged as noteworthy. His support extended beyond the immediate family and included significant others such as his teachers.

Lily similarly offered that:

"....my husband is so reassuring and very supportive...he says he fell in love with me for me. He doesn't fuff around me, he treats me quite normally. Everyone treated me normally. Everyone didn't treat me as if I was fragile."

Lily stressed about not being fussed over unnecessarily by her husband and family as they did not treat her differently after her stroke. Her husband's supportive assertion evidently normalized her space within their relationship. His positive attitude was also reflective in how others treated her. Lily, who is also a mother and wife, possibly encountered and occupied differing roles according to her capabilities as she progressed with her recuperation.

"I was always out and about, worked full-time and was a dedicated worker....I earned my own money....I was a wife...and a mother to our children. I took care of everyone and myself properly."

The above quote could be attributed to her role as a mother and wife post-stroke, and how these roles shifted to her being the one who needed to be helped by her family. By them treating her normally, it encouraged her to get back to doing the things she did prior to her stroke. Lily's experiences of support from her husband are substantiated by Murray & Harrison's (2004) study, which concluded that individuals who were already in relationships at the time of their stroke were at an advantage, as they already had someone to support them. The three participants who did not refer to partners mentioned family members, whose support and assistance was invaluable to them during the recovery process.

Generally, all four participants acknowledged the undoubted support of family and their extended networks as contributing to their recovery. They emphasized the need for empathy and understanding to address their fears, concerns, anxieties and frustrations. Support also constitutes physical assistance, as noted by the participants, who often required their family members to transport them to appointments, help them bathe and perform hygiene rituals, assist them with using cutlery and providing the physical support they required to walk.

These findings are supported by studies that conclude that stroke survivors flourish with the support from their loved ones (Hillsdon et al., 2013; Jones and Morris, 2012; Kuluski et al., 2014). When discussing the support from significant others, participants in Murray & Harrison's (2004) study found that, post-stroke, survivors encountered difficulties in finding romantic partners. They cited the use of walking aides or walking with a limp as an influential factor in their inability to engage romantically. The post stroke participants narrated this experience, as compared to those who had already been in relationships at the time of the stroke. This suggests that Ali and Jake, given their physical limitations, may potentially encounter difficulties when seeking a romantic partner. However, as later revealed by Cate, her relationship with her boyfriend terminated, and she subsequently found a supportive and patient partner.

4.7 THEME 5: STROKE AS A JOURNEY OF TRANSFORMATIVE LEARNING

The concluding theme related to all four participants, reflecting on how they attached meaning and coherence of their stroke experience. Participants narrated that, upon constant reflection of their experience, they needed to make the necessary change in their lives by slowing down, taking better care of themselves and evaluating their lives.

Ali:

"Everything happens for a reason....maybe I needed to slow down. I was over working, always trying to help others. Now I had to put myself first."

Cate:

"I broke it off with him [boyfriend at the time] as I needed to if I was going to live a good and happy life. He was a good man just not the person for me. What I'm trying to say is you need to make sure you get out all the negatives in order for you to have the strength to get better."

In Cate's experience, she evaluated her relationship with her boyfriend at the time to find that the relationship was not contributing to her recovery, and subsequently ended her relationship.

Additionally, Jake shared that he was "*given a second chance*". He also welcomed the ability to make a fresh start. Lily expressed her gratitude for being afforded the opportunity to continue watching her children grow up. All four participants emphasized that their experience afforded them invaluable life lessons that will be cherished. All participants stressed the ability of persistence in overcoming the challenge of a stroke.

This theme highlights their appreciation of the experience, which facilitated in reorganising their priorities in their lives. The consequence of these experiences have incrementally improved their personality as noted by

Cate who communicated that:

"It has been quite a journey for me... I now wouldn't change it for the world!!!! It showed me what was best for me, and it wasn't him (boyfriend at the time). Now I'm stronger and confident. My life has never been the same since but as I said I wouldn't change a thing as I'm a better, strong person. My attitude to life is now different."

Cate highlighted that the stroke was a catalyst for change in her life, and eventually altered the way she approached life. Her changed attitude post-stroke is supported by findings by Lawrence & Kinn (2012), who argued that stroke survivors' attitudes to life altered after their stroke, to make place for their new insights and understandings. Róding et al. (2003) also noted that their participants felt that the stroke had "affected them in one way or the other", causing them to "revalue their lives", allowing for "a new orientation to take place" (p.869). After her stroke, it seems Cate addressed how she acted towards the people in her life and identified what required change. She feels more confident after her stroke and this could be seen as a result of her accomplishments and overcoming the obstacles that presented themselves during the stroke. Cate reflects on her experiences of stroke as being a journey of learning and personal enhancement.

Similarly, Ali maintains that the stroke identified for her the necessary changes that she needed to be made:

"...I believe it was because I needed to slow down. I was working 2 people's work. Now I see this happened for a reason."

Ali's description of her experiences reiterates an awareness of a learning curve that demonstrated the need to reflect purposefully on her career and how that impacted on her health. As a social worker, she was cognizant of the burdens of ill-health and was totally appreciative of the recovery process. Jake expressed his gratitude by noting a second chance after his stroke:

"It has taught me the appreciation of life and the many bounties that we have been blessed with...I have learnt the meaning of perseverance and not giving up...It requires you to build your life up from scratch. This should be seen as a chance to have a fresh start."

Jake's perspective of gratitude and appreciation afforded him the determination to recover. Whereas Jake expressed his appreciation of being given a fresh start to begin again, it appears Lily learned that her experiences could have been worse, when she encountered other stroke survivors who were confronted by more severe challenges than her. The concept was also noted in Kuluski et al. (2014, p. 8) and Roding et al. (2003), where participants were also grateful and appreciative that it "could have been worse".

Lily reflected that:

"I am a better person now completely. It's not "oh shame", it's 'I am still alive, I can still watch my kids grow up... I considered myself one of the lucky ones, when I saw patients in there....'"

The interpretation of Lily's experience of stroke is one of gratitude, as she can watch her children grow and likely play a significant role in their development. Lily felt fortunate to be able to recover, especially when she encountered other stroke survivors in the Rehabilitation Unit who would be unable to walk again. She did not communicate self-pity about her circumstances as a result of the stroke. Rather, she acknowledged the opportunity to continue to raise her children. It can be inferred that Lily's experience involved gratitude and determination and, furthermore, it indicated her strength of character and resilience.

The journey and its lessons are also supported by Burton (2000), who concluded that participants would be unable to forget their stroke, explaining that it would be important to them for the rest of their lives. Each of the participants in the study indicated that their stroke had had significant impact on how they will live their lives, using it as a measure of learning and a journey they are still successfully navigating.

As discussed above, the inherent interconnectedness was present amongst the themes as both challenges and experiences. Frustration at dependency, reliance on others, fears of being judged and misunderstood are some of the pertinent experiences as described by young adult stroke survivors in this study. Additionally, the support of family, friends and partners are viewed as being substantial to the post-stroke recovery journey in its entirety, which is seen to offer transformational life lessons.

CONCLUSION

In conclusion the presentation of the five themes sequentially suggests the progression of recovery and healing, as it occurs from initial diagnosis, navigating of the challenges and experiences, to appreciating the support and reflecting on the journey within a positive perspective. And in true phenomenology tradition, it became evident to the researcher that participants were initially, as Theme 1 suggests, met with shock and surprise, progressed to acceptance, and finally viewed the experience as being transitional. All participants confirm the negative event progressed into a positive experience as they adjusted post-stroke. It is vital to note that each of the four participants attained this stage of positive acclimatization without psychological assistance. This suggests that the support they experienced is assumed to have guided them through their challenges and difficult experiences of stroke, to become totally functional.

CHAPTER FIVE: CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

The purpose of this final chapter is to present the conclusions that emanated from the analysis of the study and thereafter present some recommendations.

In summary the research questions that guided this study were twofold:

1. What are some of the lived experiences of young adult survivors of stroke?
2. What are the major challenges faced in young adults post-stroke?

The following objectives explicitly translated into the two research questions:

- I. To gather lived experiences from four young survivors of stroke.
- II. To identify the major challenges faced by young adults post-stroke.

The Email Facilitated Qualitative Interviews generated data from four young adult stroke survivors, as captured in the previous chapter. The narratives of the participants yielded five major themes that were significant to their pertinent experiences and challenges. In addition, these themes shared a fair degree of interconnectedness, demonstrating the extricable relationship with each aspect of their lived experience. The five themes as detailed in the previous chapter are the following:

1. The Initial Response of Shock and Surprise
 - 1.1. Appropriate response by medical practitioners
2. Frustration Due to Limitations
 - 2.1 Dependency on others due to limitations
 - 2.2 Frustration as a result of dependency
 - 2.3 Frustration at slow progress
 - 2.4 Post-stroke frustrations within the intimate relationship
 - 2.5 Temporary loss of independence
3. Perceived Fear of Judgment
 - 3.1. Being judged on physical restrictions
 - 3.2. Being judged on restrictive cognitive capabilities
4. The Significant Role of Family Support
5. Stroke as a Journey of Transformative Learning

As stated earlier, the interconnectedness between the above themes was interpreted and understood from experiences and challenges expressed by participants. Furthermore, the sequential presentation of the themes highlighted the progressive nature of the young adults' experiences of stroke.

5.2 CONCLUSIONS FROM FINDINGS

From the aforementioned themes the following conclusions were reached. One of the major conclusions from the analysis of the study was that the experiences and challenges encountered by the young adult stroke survivors were interpreted as progressive in nature. The progression lead from the understanding and recognition of the negative consequences and side-effects of stroke for the participants. One negative consequence was being dependent and reliant on significant others, often resulting in feelings of helplessness, frustration and sheer annoyance. Furthermore, the process of learning and adapting to the challenges and negative consequences was shown to occur in a sequential manner. The successive experience facilitated personal growth, understanding and meaning for participants. Even though they continue to encounter challenges, the experience helped them to move into a transformative space of recovery and self-discovery.

Their overall experience in hindsight afforded them positive reflection, which motivated them to reorganise their priorities. The participants contemplated the deeper meaning of their lives and maintain their strength by being motivated to encounter further challenges. They expressed their appreciation for the blessings they received and acknowledged, with pride, their resilience as young adult stroke survivors.

An additional salient conclusion was the prominence of supportive structures in facilitating the recovery process. Participants acknowledged their family support in assisting them physically and emotionally.

It can also be concluded from the narratives that, in the process of their recovery, there was an absence of any professional psychological intervention, since their supportive structures were deemed adequate and sufficient throughout their experience as young survivors of stroke.

5.3 RECOMMENDATIONS

From the analysis of the study the following recommendations are offered:

5.3.1 Medical services

5.3.2 Psychological interpretations

5.3.3 Creating awareness

5.3.4 Public health system

5.3.1 Medical services.

In South Africa the incidences of stroke are on the increase, as approximately 8760 strokes are experienced by young adults annually (www.heartfoundation.co.za/what-stroke). Invariably accessing immediate medical attention is the first service a potential stroke survivor will contemplate. Hence, the medical team becomes pivotal in contributing to how a stroke survivor interprets their diagnosis. As experienced by Ali, as she encountered the medical team, it is recommended that a full medical history, as protocol dictates, be taken of all patients, to determine their suitability to receive medication. Furthermore, a full medical history would assist in making the appropriate diagnosis that will inform appropriate treatment. This is validated by www.medicalprotection.org and Bryer *et al.* (2010, p.762), who strongly urges that in order to make a reasonable diagnosis, certain essential requirements are necessary. Amongst these is the importance of taking a full medical history from the patient – or a family member if the patient is incapacitated. According to Jones and Mandy (2000), as cited in (Røding *et al.*, 2003),

“it is appropriate to ask whether health care actually disempowers stroke patients instead of using empowerment strategies for their recovery.”

In line with this, it is also recommended that, although the medical team influences the recovery process, stroke patients can also take responsibility of their own learning with regard to their medical condition. This affords the stroke survivor the capacity to empower themselves, create awareness and take responsibility for learning about their unique condition as they proceed through the recovery phase.

5.3.2 Psychological interpretations.

Beyond being another young adult stroke survivor, the researcher, as a professional clinician, observed that healing occurred for all four participants even in the absence of psychological intervention. This could indicate that if the immediate supportive mechanisms are adequate, psychological intervention may not be warranted – as discussed in Theme 4. In addition to this, the young adult stroke survivors are likely to possess inner resilience, given their young ages, which can be used to negotiate a quicker recovery time.

5.3.2.1 For the young adult survivor.

As defined by Maslow's hierarchy of needs (Tay & Diener, 2011), humans are driven to satisfy the basic biological and physiological needs before progressing to meet an incrementally higher growth need. Therefore it is understood that immediate attention will be given to the physical needs of the stroke survivor thereby offering physical rehabilitative services first. It is recommended that simultaneous psychological intervention be afforded to the young adult stroke survivor and their families. The psychological intervention should be aimed at providing immediate crisis intervention to help the individual process the *Initial Response of Shock and Surprise*. Teater (2012, p.196) emphasises that crisis intervention "focuses on mobilizing clients' strength and resources in order to overcome a crisis situation and improve their level of coping, confidence and problem-solving."

The seven stages of the crisis intervention model are appropriate and demonstrate how the experiences and challenges of stroke in young adults involves significant others. This emphasises what role psychology will play in the development of coping mechanisms post-stroke in young adults. Thereafter, Supportive Therapy can be used to manage the non-visible consequences of stroke, such as the *Frustration* experienced as young adult stroke survivors negotiated their limitations and, as a result, their *Dependency* on others.

Kanel (2012, p.12) maintains that in a crisis "feelings of bewilderment, confusion and conflict present themselves." Cate felt conflicted within herself, as her partner was not understanding and she perceived him to be judgmental. Ali and Lily explain their feelings of shock, disbelief and surprise when told of their diagnosis. The exploration of Coping Skills can be used as another psychological intervention to help these survivors with these feelings and the *Perceived Judgment* they experience.

Psycho-educational services are recommended to facilitate the overall adjustment process, and to assist the survivor – as well as the relevant caregivers – with re-integration into the home life post-stroke. Psychological intervention is also recommended for the duration of rehabilitation, as this process has proven to be tedious and emotionally challenging, as expressed by the participants. Furthermore, psycho-educational service is recommended for the stroke survivor to help them prepare to enter back into their role within the family and to address role-reversal, if present.

It is recommended that patients be well-prepared for their discharge home, so as to negate unwarranted expectations, which may cause frustration, as mentioned by Ali. Therefore, a holistic approach to treatment and management is recommended. This can be achieved through psycho-education and the management of the young adult patient by a

multi-disciplinary team, comprising of professionals in neurology or cardiology, physiotherapy, occupational therapy, speech therapy, psychiatry if necessary, and psychology, in order to educate the patient on what to expect and how to navigate potential challenges and cope with the adjustment. These aforementioned recommendations place the service of psychologists in an indelible position to the stroke survivor in a bid to provide the care to ensure optimal psychological wellbeing.

5.3.2.2 For the family, caregivers and partners.

Where supportive mechanisms need strengthening, more attention should be provided to psycho-educational assistance within a supportive framework, whereby families and relevant caregivers of young adult stroke survivors are informed on skills such as patience, to practice being non-judgmental and to explore the impact of role reversal – as elaborated on and analysed in Chapter Four. These reversals of stereotypical roles were challenged as described by Ali, Cate, Lily and Jake. The aim of psycho-education should focus on how the family can create conducive environments and assist in preparing them for the return of the young adult stroke survivor back into the home with patience and without judgment.

Becvar & Becvar (2009, p.277) highlight “adaptability...as the capacity of a family to function competently in effecting change and tolerating differentiation.” Family therapy is a recommendation for the stroke survivor and their families to promote care, adjustment at home and overall psychological wellbeing for both parties.

For the discussion of Cate’s difficulties experienced in her intimate relationship a recommendation is made for couple’s therapy as the post-stroke consequences have been shown to impact the relationship. In terms of couple’s therapy, several counselling techniques are available. Emotion-Focused Couples Therapy, developed by Dr Susan Johnson, focuses on the drama of a distressed couple (Prochaska & Norcross, 2010). It has also proven useful for family counselling. The therapy repositions the stance of each partner to create new, beneficial interactions in the relationship. Alternatively, The Gottman Method of couples counselling, created by Doctors John and Julie Gottman, can be used when a couple are under strain. This method teaches the couple how to develop love maps, which highlight the worries, stresses, joys, hopes, and history of their partners. In doing so, the psychological world of each partner is highlighted. Through the expression of respect and appreciation for each partner, fondness and admiration are fostered. Within this method, the focus lies on conflict management as opposed to conflict resolution (Gurman, 2008). These are suggestions of the role psychology can play based on the findings of this study.

It is important to note that psychological services were not offered to any of the participants at any time during their stroke experiences. It is recommended that psychological intervention be introduced as early as possible and as soon as the survivor is physically and cognitively stable enough to engage with a psychologist. Even in the absence of pathological adjustment to the consequences of stroke, it is still recommended that psychological intervention be offered, albeit of a supportive, psycho-educational nature.

5.3.3 Creating awareness.

Stroke statistics in South Africa, are alarmingly high, with approximately 8760 strokes presenting in the young annually. Therefore, awareness of the contributing risk factors of stroke needs to be addressed in order to combat this growing health problem. By creating awareness of the risk factors, and of stroke in itself, the aim is to decrease the rate of incidence and increase the efficiency of treatment. Awareness of adopting healthier lifestyles in order to decrease potential risk should be addressed. Awareness campaigns should be run frequently to promote healthy eating habits, frequent exercise, warnings of excessive alcohol consumption and tobacco use, and encouragement for frequent medical assessments of blood pressure and cholesterol. By creating awareness around these factors, the issues of risk factors will be addressed. Posters can be put up at public hospitals to inform people of the risk factors, and how to minimise their risk of stroke. Local community newspapers and national television media should run advertisements in conjunction with national bodies – like the Heart and Stroke Foundation – to create awareness, promote stroke knowledge and how to decrease the risk of stroke by adopting healthier lifestyles.

Given the inefficient treatment described by Ali and Lily, a recommendation is made to increase response time to stroke symptoms, so that effective treatment can be sought as early as possible.

This final recommendation is that the F.A.S.T. test be utilised. The purpose of this test is to assist people in assessing for stroke presentation. The acronym for the test is described below and is strongly recommended by the Heart and Stroke Foundation of South Africa (www.heartfoundation.co.za/how-recognise-stroke), Headway Natal (www.headway.org.za) and My Stroke (www.mystroke.co.za).

F = Examine the individual's face to assess for *Facial Drooping*.

A = Ask the individual to *raising both arms* to assess if one or both sway and/or fall,

S = Assess the individual's speech to determine if they have speech difficulties or the inability to speak, and

T = Understanding the urgency of the situation if the abovementioned criteria are met; time is of the utmost importance and immediate help should be sought.

This is an at-home test and can assist in obtaining medical assistance within the 'golden hour', as suggested by www.mystroke.co.za. The promotion of this test across all media platforms was evident in October 2015, which has been officially declared as Stroke Awareness Month, as well as Global Stroke Day, being celebrated on 29 October each year. Privately run hospitals in the Ethekeweni district of Durban, KwaZulu-Natal, including Ethekeweni Hospital and Heart Centre and Netcare Umhlanga Hospital have been promoting their stroke management facilities during this month, by advertising in local community newspapers and on national television, highlighting that their aim is to provide time-efficient treatment. Their protocols have been amended to: "Triage to thrombolysis in 60 minutes", which adheres to the recommendations made by www.mystroke.co.za.

5.3.4 Public health system.

In terms of the burden of stroke in South Africa, as discussed in Chapter Two, it is understood that medical research and financial preference is provided to the HIV/AIDS and Tuberculosis epidemics (Fritz, 2006). This has resulted in budget confinement, with minimal resources left for the growing incidence of stroke in South Africa. It is suggested that some intervention is supported by the Government to provide the public health systems with equipment, training and setting protocols in place on how to effectively diagnose, treat and manage stroke. More recently, Bryer *et al.* (2010, p. 756-757) offer their suggestion, which is in line with the researcher's recommendations, as some protocols are already in existence according to these authors:

"For improved stroke care, provincial health authorities need to re-organise existing resources within district and secondary hospitals in accordance with national guidelines and the National Department of Health stroke initiative in order to provide a service with defined protocols for stroke care. Established units such as those in the public sector of the Western Cape could serve as a model for the re-organisation of existing resources to provide more effective stroke care without necessarily incurring additional costs."

This could be replicated in KwaZulu-Natal and in other provinces to maximise on creating awareness. According to www.mystroke.co.za/stroke-units, two government hospitals within KwaZulu Natal have employed specialists who are equipped to treat strokes. However, specific procedures may not be established as yet.

5.4 CONCLUDING REMARKS

It is apparent that this study can contribute toward creating further awareness that stroke can affect the young, as noted by the young adult survivors in this study. This will also dispel the myth that the condition is only experienced much later in life. To effectively create awareness around the experiences of young adult stroke survivors, the experiences and challenges they face should be carefully considered. This will help facilitate the aforementioned recommendations.

It is recommended that future studies be conducted, and that future research employs a longitudinal approach to observe the evolving experiences during recovery post-stroke. Additionally, it is recommended that this study be conducted with 1) a larger sample and 2) with young adults of diverse backgrounds to determine the apparent and unapparent challenges and experiences across participants.

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APPENDIX A
Interview Schedule

Question:	Question Theme
1.	What are your experiences of having a stroke as a young or middle aged adult?
2.	When describing your stroke try to remember what you were feeling, thinking and doing at the time.
3.	What were you feeling and thinking about when you were told you had had a stroke? Describe this experience.
4.	Describe your experiences of recovery / rehabilitation and what it was like to go through this as a young or middle aged adult.
5.	What was happening around you that contributed to the way you were feeling?
6.	What changes or challenges did you face and how did this make you feel?
7.	Where possible please provide as many examples as you can to illustrate your description of your experience.
8.	What recommendations would you make for other young adults who have had stroke?

APPENDIX B1
Letters of Permission to Gatekeeper

The Stroke Survivors Foundation

1 June 2014

Postnet Suite 311

Private Bag X4

Hout Bay

7872



For attention: Mr George Scola

**REQUEST PERMISSION OF CONTACT DETAILS OF YOUNG ADULT STROKE
SURVIVORS TO PARTICIPANT IN A RESEARCH STUDY**

Dear Mr Scola

My name is Sumaya Jeewa, and I am currently a Masters Clinical Psychology postgraduate student at the University of KwaZulu-Natal, Howard College in Durban. One of the requirements of my degree is to complete a dissertation. The research I wish to conduct for my Master's dissertation involves exploring the experiences of young adult stroke survivors. I am hereby seeking your assistance in obtaining contact with 4 - 6 stroke survivors.

The age range for potential research participants is between 18 and 45 years (at the time of the stroke). It is preferable for participants to have access to computers, internet connectivity and email accounts as this will be the method of contact between the researcher and the participants. Young adults who will qualify to be part of this research must have the capability of recalling their stroke experiences and describing these to the researcher. The title of the research project is "Stroke of Luck: Phenomenologically understanding the experiences of young adult stroke survivors". This project will be conducted under the supervision of Ms Lucinda Johns, a lecturer at UKZN, Discipline of Psychology.

I have provided you with a copy of my dissertation proposal which includes copies of the email-facilitated interview schedule and Informed Consent Forms for participants to be used in the

in the research process. A copy of the approval letter from the Research Ethics Offices: (HSSREC) at University of KwaZulu-Natal will follow shortly.

Upon completion of the study, I undertake to provide Hardy and Associates with a bound copy of the full research report. It is hoped this research will assist in increasing awareness around stroke and the experiences it has on young adults.

If you require any further information, do not hesitate to contact me on 082 677 4477 or at sumayajeewa@yahoo.co.uk. My supervisor can be contacted on 082 879 5512 or at johnsl@ukzn.ac.za. You are also welcome to contact Ms P Ximba from HSSREC on 031 260 3587.

Thank you for your time and consideration in this matter.

Yours sincerely,



Sumaya Jeewa

Researcher

Email: sumayajeewa@yahoo.co.uk.

Contact details: 082 677 4477



Lucinda Johns

Research Supervisor

Email: johnsl@ukzn.ac.za

Contact details: 082 879 5512

APPENDIX B2
Letters of Permission to Gatekeeper

Dr Roseanne Hardy

1 June 2014

Hardy and Associates

14 Nutell Gardens

Morningside

Durban

Contact Details: (031) 312 1248

Email: rhardy@iafrica.co.za



**REQUEST PERMISSION OF CONTACT DETAILS OF YOUNG ADULT STROKE
SURVIVORS TO PARTICIPANT IN A RESEARCH STUDY**

Dear Dr Hardy

My name is Sumaya Jeewa, and I am currently a Masters Clinical Psychology postgraduate student at the University of KwaZulu-Natal, Howard College in Durban. One of the requirements of my degree is to complete a dissertation. The research I wish to conduct for my Master's dissertation involves exploring the experiences of young adult stroke survivors. I am hereby seeking your assistance in obtaining contact with 4 - 6 stroke survivors.

The age range for potential research participants is between 18 and 45 years (at the time of the stroke). It is preferable for participants to have access to computers, internet connectivity and email accounts as this will be the method of contact between the researcher and the participants. Young adults who will qualify to be part of this research must have the capability of recalling their stroke experiences and describing these to the researcher. The title of the research project is "Stroke of Luck: Phenomenologically understanding the experiences of young adult stroke survivors". This project will be conducted under the supervision of Ms Lucinda Johns, a lecturer at UKZN, Discipline of Psychology.

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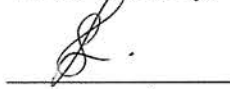
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Thank you for your time and consideration in this matter.

Yours sincerely,



Sumaya Jeewa

Researcher

Email: sumayajeewa@yahoo.co.uk.

Contact details: 082 677 4477



Lucinda Johns

Research Supervisor

Email: johnsl@ukzn.ac.za

Contact details: 082 879 5512

APPENDIX B3
Letters of Permission to Gatekeeper

Headway Natal
11 Menston Road
Westville
3630

1 June 2014



Contact Details: (031) 266 2709

Website: www.headway.org.za

For attention: Mr Ian Vowles

**REQUEST PERMISSION OF CONTACT DETAILS OF YOUNG ADULT STROKE
SURVIVORS TO PARTICIPANT IN A RESEARCH STUDY**

Dear Ian Vowles

My name is Sumaya Jeewa, and I am currently a Masters Clinical Psychology postgraduate student at the University of KwaZulu-Natal, Howard College in Durban. One of the requirements of my degree is to complete a dissertation. The research I wish to conduct for my Master's dissertation involves exploring the experiences of young adult stroke survivors. I am hereby seeking your assistance in obtaining contact with 4 - 6 stroke survivors.

The age range for potential research participants is between 18 and 45 years (at the time of the stroke). It is preferable for participants to have access to computers, internet connectivity and email accounts as this will be the method of contact between the researcher and the participants. Young adults who will qualify to be part of this research must have the capability of recalling their stroke experiences and describing these to the researcher. The title of the research project is "Stroke of Luck: Phenomenologically understanding the experiences of young adult stroke survivors". This project will be conducted under the supervision of Ms Lucinda Johns, a lecturer at UKZN, Discipline of Psychology.

I have provided you with a copy of my dissertation proposal which includes copies of the email-facilitated interview schedule and Informed Consent Forms for participants to be used in the

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If you require any further information, do not hesitate to contact me on 082 677 4477 or at sumayajeewa@yahoo.co.uk. My supervisor can be contacted on 082 879 5512 or at johnsl@ukzn.ac.za. You are also welcome to contact Ms P Ximba from HSSREC on 031 260 3587.

Thank you for your time and consideration in this matter.

Yours/sincerely,



Sumaya Jeewa

Researcher

Email: sumayajeewa@yahoo.co.uk.

Contact details: 082 677 4477



Lucinda Johns

Research Supervisor

Email: johnsl@ukzn.ac.za

Contact details: 082 879 5512

APPENDIX C1

Gatekeepers Permission Letter



Attention: Sumaya Jeewa
Research student
UKZN

Email: sumayajeewa@yahoo.co.uk

Hi Sumaya

Re: Young Adult Stroke Survivors research study

We agree to provide you with the required participants for your research and support where we can. The candidates are nominated on condition that we obtain approval from their families and we look forward to receiving a copy of your dissertation thereafter.

We wish you success in your research.

Best regards

A handwritten signature in black ink, appearing to read "Ian Vowles".

Ian Vowles
Manager
Headway Natal
Tel: 031 2662709/2662713/2660045
www.headway.org.za

11 Merston Road
Westville, 3529
Tel: 031 266 2709 /
031 266 0045
Fax: 031 266 2713
Email: headway@donortrust.co.za
www.headway.org.za

HEADWAY
A NON-PROFIT
ORGANISATION TO
ACCOMMODATE
ADULT AND YOUNG
ADULTS WITH
HEALTH ISSUES

APPENDIX C2
Gatekeepers Permission Letter



Dr R M Hardy
Regd Health Professions Council of S A
Practice No: 8645442
Psychologist (practicing exclusively in the field of neuropsychology)
Tel: (031) 3121248
Fax: 086 031 3121248
Email: rhardy@iafrica.com
VAT No: 4650245303

The Manor House
14 Nuttall Gardens
Morningside
Durban
4001

28.05.2014

c/o Lucinda Johns
Research Supervisor
University of Kwa-Zulu Natal

Dear Sumaya

RE: YOUNG ADULT STROKE SURVIVORS RESEARCH STUDY

Further your request, I confirm that I will be able to give you access to our patient database in order for you to conduct your research on stroke survivors once you have received ethical clearance.

Yours sincerely,

Dr. Rosanne Hardy
FULL MEMBER: SA Clinical Neuropsychological Association

APPENDIX C3
Gatekeepers Permission Letter



The Stroke Survivors Foundation

[Section 21] / Reg No: 2010/002369/08 / NPC Number: 083-865
Postnet Suite 311
Private Bag X4
Hout Bay
Cape Town 7872

[T] 082 889 1800
[F] 086 579 9796

[E] info@strokesurvivors.org.za
[W] www.strokesurvivors.org.za

YOUNG ADULT STROKE SURVIVORS TO PARTICIPANT IN A RESEARCH STUDY

Dear Ms Jeewa

Thank you for approaching the SSF and also giving us the opportunity to participate in your study of stroke and the effects of stroke in younger people.

As you are well aware, stroke is occurring more often and it's affecting younger and younger people. It is the second biggest killer and the number one cause of disability in South Africa...a harsh reality for younger people!

We are pleased to offer our support and advocacy of your dissertation and wish you all the best in your endeavour!

Let's create further awareness of Stroke!

Thank you

Yours sincerely



George Scola
Stroke survivor
082 306 3214



OUR MISSION

To create a national network that provides post-discharge rehabilitation & support for stroke survivors, their families & caregivers

Directors: GS Scola, CD Murray

APPENDIX D

Letter of Participation and Information

University of KwaZulu-Natal - Masters in Clinical Psychology Research Project “A Phenomenological understanding of the experiences of young adult stroke survivors”

Dear Participant

I am currently registered for my Masters in Clinical Psychology at the University of KwaZulu-Natal, Howard College campus. My research interests lies in the effects stroke has on young adults. More specifically, I am interested in your personal experiences of having survived a stroke and how it has impacted on your life. A qualitative phenomenological framework will be adopted. This will allow for reflection of your understanding and experience of stroke.

I will contact you telephonically to explain the research study. This will build rapport, respect and a trustworthy relationship. Email facilitated qualitative interviews have been selected as the method of gathering information. This will entail an interview schedule that will be emailed to you should you decide to participate in the study. You will be required to answer the questions and email them back to me. Once responses have been received I will contact you telephonically again. This will grant me the chance to thank you for participating in the research study and will additionally offer the opportunity to clarify the responses given, should this be necessary.

The interview questions are:

- I. What are some of the lived experiences of young adults who have had stroke?
- II. What are the major challenges faced made in young adults post-stroke?
- III. How has the experience of a stroke contributed to stroke survivors understanding or meaning of stroke?
- IV. How has the experiences and challenges shaped the meaning and understanding of a stroke by survivors?
- V. What recommendations do young adult stroke survivors have for others?

I am aware of time constraints and work commitments that may be present. Your personal stories and reflective experiences will help to enhance the understanding of strokes in young adults. Your potential input is viewed as valuable and will be appreciated.

If you are interested in participating in my research project please email or contact me.

If you have any queries about my project, please contact either me or my supervisor Lucinda Johns (Registered Counselling Psychologist and Lecturer).

Thanking you in advance.

Kind regards



Sumaya Jeewa

Hons BA (Psychology)

Currently completing Masters in Clinical Psychology 2013 / 2014

Contact details of researcher:

Sumaya Jeewa

Cell: 082 677 4477

Home: 031 572 7478

Email: sumayajeewa@yahoo.co.uk

Contact details of Supervisor:

Lucinda Johns

Cell: 082 879 5512

Work: 031 260 7620

Email: johnsl@ukzn.ac.za

APPENDIX E

Informed Consent Form

University of KwaZulu-Natal Howard College campus

Masters Research Project

Consent Form

Thank you for agreeing to participate in this study. This study will take place between August 2014 and February 2015. This form outlines the purpose of the study and provides the necessary information pertaining to your involvement and rights as a participant.

This research project is for the purpose of attaining a Masters in Clinical Psychology at the University of KwaZulu-Natal, Howard College campus. This research project will be a qualitative descriptive phenomenological study using Email facilitated interviews to provide an understanding of your personal experiences of stroke.

This project was chosen as the researcher has a professional and personal interest in strokes experienced by young adults.

Due to practical constraints this interview will be done via email. This will give you the necessary time to reflect on the research questions before answering. You will not be given any monetary payments for participating in the study. The results will help us to understand how strokes have affected young adults.

Participants are welcome to ask any questions at any time about (the methodology and data analysis of) the research project. If you wish to contact me after the data collection phase a debriefing session can be arranged, my contact details are below.

I guarantee the following conditions will be met:

1. Your real name will not be used in the transcription, collection or in the write up of the thesis, its subsequent publication or in the presentation of the research project. Once data has been received, a hard copy will be printed and stored securely. Thereafter your responses will be copied into a Word Document and you will be assigned a coded number so as to maintain anonymity. These assigned coded numbers will only be known to the supervisor supervising this project and to myself.
2. The emailed documents will not be used for anything else but for the purpose of this study.

3. You will not be at any disadvantage should you choose not to participate in the study.
4. You may also refuse to answer particular questions if you don't feel comfortable answering them.
5. Your participation in this research project is entirely voluntary and you have the right to withdraw at any time, for any reason, without prejudice. In case you want to withdraw information given after the interview, please do so by contacting me on the contact details below (please detach).

Please sign the following in acknowledgment of your participation and understanding of the document.

Declaration of acknowledgment

I..... (First and Last names of participant) hereby confirm that I comprehend the contents of this document and the nature and purpose of the research study, and I consent to participating in the research study.

I understand that I am free to withdraw from the research at any time, should I so desire.

SIGNATURE OF PARTICIPANT

DATE

.....

.....

SIGNATURE OF RESEARCHER

DATE


.....

20/12/2014
.....

Who to contact if you want to know, or if you have a problem at any time:

If you would like to obtain more information of your rights as a participant in this study please contact:

Ms P. Ximba, University of KwaZulu-Natal, Telephone - 031 260 3587

APPENDIX F

Questionnaire Guidelines

University of KwaZulu-Natal Howard College campus

Masters Research Project

Data Collection

Masters in Clinical Psychology research project:

“A Phenomenological understanding of the experiences of young adult stroke survivors”

Dear Participants

Thank you for agreeing to participate in my research study. Your help and participation is greatly appreciated. This project would not have been made possible without all of you.

The procedures are as follows:

Firstly, whilst answering the interview questions, relax and take your time reflecting back on your experience of stroke. I would appreciate it if you could furnish me with your responses within seven (7) days. Take the time to answer the questions appropriately.

Secondly, because this is a masters research dissertation could you please answer the attached interview questions to the *best of your ability*, with *in-depth description*, and possibly *give examples* in your description of your experiences. I will need to use this data for the write up of my results section in my project so the more input and detailed description you give me the more information I can elicit for my write up.

Thirdly, when describing your experiences try to do so by remembering what you were *feeling, thinking, doing, what was significant for you, what was happening around you that contributed to your feelings, what changes or challenges you faced, how these made you feel, tell me more about how all these made you feel, and where possible please provide examples to further describe your experience*. These are just guidelines that may help you think about your experiences a little more and will help me elicit a fuller response to the interview questions.

Lastly, please **type** the answer to each question on a **new page** and **label each answer** clearly. Please try to answer each question to the best of your ability.

After receiving your responses I may contact you for clarification if necessary on responses that I do not fully understand.

Thanking You



Sumaya Jeewa

If you have any further enquiries feel free to contact me:

Contact details:

Sumaya Jeewa

Cell: 082 677 44 77

Home: 031 572 74 78

Email: sumayajeewa@yahoo.co.uk

APPENDIX G

Ethics Application – Full Approval



09 December 2014

Ms Sumaya Jeewa (206500639)
School of Applied Human Sciences – Psychology
Howard College Campus

Dear Ms Jeewa,

Protocol reference number: HSS/1228/014M

Project title: A phenomenological understanding of the experiences of young adult stroke survivors

Full Approval Notification – Committee Reviewed Protocol / Amendment

This letter serves to notify you that your response and request for an Amendment received on 08 December 2014 regarding our letter of 12 November 2014 was reviewed by the Humanities & Social Sciences Research Ethics Committee, has now been granted **Full Approval**.

Any alterations to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach/Methods must be reviewed and approved through an amendment /modification prior to its implementation. Please quote the above reference number for all queries relating to this study.

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

Best wishes for the successful completion of your research protocol

Yours faithfully

Dr S Singh (Chair)

/ms

cc Supervisor: Ms Lucinda Jones
cc Academic Leader Research: Professor D McCracken
cc School Administrators: Ms Ausie Luthuli

Humanities & Social Sciences Research Ethics Committee

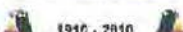
Dr Shenuka Singh (Chair)

Westville Campus, Govan Mbeki Building

Postal Address: Private Bag X54001, Durban 4000

Telephone: +27 (0) 31 260 3587/8350/4557 Facsimile: +27 (0) 31 260 4608 Email: kimbab@ukzn.ac.za / snymam@ukzn.ac.za / mohung@ukzn.ac.za

Website: www.ukzn.ac.za



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APPENDIX H

Transcript Sample

The following is a sample of a transcript from one of the participants in this study. Highlighted are the initial notes made when the transcript was read and re-read several times over. Emerging title themes were recorded in the right hand margin on the hard copy of the transcript, however are indicated in the following appendix.

The following is a sample of a transcript from one of the participants in this study. Highlighted are the initial notes made when the transcript was read and re-read several times over. Emerging title themes were recorded in the right hand margin on the hard copy of the transcript, however are indicated in the following appendix.

What are your experiences of having a stroke as a young adult?

It's been quite a journey for me, I've gone through many emotions (highs and lows) and I've found it to be very tough and challenging, but once I let myself experience and go through all the emotions I now wouldn't change it for the world!!!!!!

In the beginning I went through every emotion, laughed a lot then cried so much. I was depressed for 3 weeks. Then I was very angry. It was a shock to me. Went in for something else, came out with a stroke. Didn't register what a stroke is. I couldn't talk for 3 weeks. Trained muscles in my throat and mouth to learn to talk. It was very difficult. I cried in rehab. Worked my arm, was the worst part of body; I would break out in tears. My boyfriend was overseas. He didn't go through it all with me.

I kept wondering would I be normal. Would I be accepted into the world? Would I look the same? Very conscious about how I looked to others? Would I be able to work again? I thought about my future, would I be able to look after my children?

Rehab was so hard. You do not see the future; you are just focused on the moment – which was very painful and difficult. My mom returned home when I went to rehab....and being alone through the rehab process was very scary. But I made friends after a week.

When describing your stroke try to remember what you were feeling, thinking and doing at the time.

I had a stroke when I was in an induced coma and on a ventilator so I do not remember the feeling of having a stroke. If I had to have one now, I wouldn't know what it feels like. My boyfriend watches me. I tell him about any little feeling I get. I get anxious with any new feeling, and I tell people and they watch me.

What were you feeling and thinking about when you were told you had had a stroke? Describe this experience.

Commented [S31]: Stroke as a Journey

Commented [S32]: Accepting the experience of stroke

Commented [S33]: Shock

Commented [S34]: Voiceless;
Limitations; Loss of Abilities

Commented [S35]: Overcame Difficulties

Commented [S36]: Emotional

Commented [S37]: Regaining Normality; Anxieties → regaining walking and talking abilities; being accepted back into the world; Physical Appearances; Returning to Work; Fulfilling Responsibilities.

Commented [S38]: Difficult seeing pass the present constraints

Commented [S39]: Initial response of Rehab –lonely, afraid and painful

Commented [S310]: Anxiety with regard to health and possible future strokes; Not knowing what a stroke feels like is anxiety provoking

When I was taken off the ventilator and was coming out the induced coma I was told I had had a stroke. It took me a long time to really understand the situation and come to terms with what this meant. When I did realize I was scared and worried if I was ever going to be able to be normal. In my siltation I had lost a lot of weight and muscle from lying on the bed for three and a half weeks. This meant I couldn't walk, talk or swallow. I could only voice my feelings after about 2 weeks when my voice came back. I was high on morphine. It took a week to focus and understand what people were saying. I couldn't speak at the time. I had all the feelings bottled inside. I could not get the answers I needed. I was very confused and overwhelmed.

I had lost a lot of weight – I could not sit up on my own and needed help to get seated on my bum. They would sit me up and I would fall over. I had to strengthen my core. I was worried I would never walk again. I couldn't speak. I couldn't express my feelings at the time or ask questions. I wanted to know what else I could do to recover. My voice came back and then went away for 2 days. It was a very scary time when thought I wouldn't speak again.

Describe your experiences of recovery / rehabilitation and what it was like to go through this as a young adult.

Recovering was very hard but I was taken to a rehab that really helped me with all aspects of my recovery. I had emotional support as well which helped me. My goal was to talk out the rehab and then I would focus on my arm.....when working my arm; wow was that tiring. I could draw on being young – previously vibrant. My gran was in her 60s when she had a stroke and recovered fully from her stroke. So I had to make sure I walked out of that rehab centre. Everyone kept saying age was on my side. So this gave me hope. I drew strength from gran's recovery. I am not still fully recovered. I have to accept myself the way I am. Kept thinking about the future. Kept thinking about looking after my kids and did not want others looking after my kids. I could not move my fingers when I left the hospital. I could not even twitch them. When it twitched for the first time it just gave me a lot of hope. Small improvements at the start mean so much when you are feeling down. I had a lot of emotional support my parents were by her side throughout. My mom was there every minute. She laughed with me and let me cry when I needed to. She held me when I needed to cry. My siblings were also so supportive. (**** began crying****). My mom was my rock. Love from my family motivated me to get better. Friends were visiting me– some of whom I didn't even know.

What was happening around you that contributed to the way you were feeling?

I had so much positive energy around me and my family was my rock. Without them I would never had had the strength to fight the way I did. They all motivated me. Everyone visited me, from far. People supported my family and this meant a lot to me because they also went through this with me. Was worried about how my family felt. Luckily others were there to lift them up. Docs told parents to prepare for the worst, mom prayed and felt calm. When she told me this it motivated me further to learn to walk etc. received letters from overseas. Mom

Commented [SJ11]: Could not comprehend diagnosis

Commented [SJ12]: Initial responses

Commented [SJ13]: Regaining normality

Commented [SJ14]: Limitations

Commented [SJ15]: Voiceless

Commented [SJ16]: Emotional

Commented [SJ17]: Needing help; Physical Limitations; Feeling dependent on others

Commented [SJ18]: Concerns about recovery; Anxieties

Commented [SJ19]: Fear on never being able to speak; feeling trapped; unable to communicate; frustrating and scary; bottling of feelings; unable to have concerns pacified, could not express worries or ask questions; helplessness

Commented [SJ20]: Anxieties regarding recovery

Commented [SJ21]: Experience of Rehab; Aspects of recovery

Commented [SJ22]: Importance of Emotional Support

Commented [SJ23]: Drawing on youth / young age to help recover

Commented [SJ24]: Drawing on youth / young age to help recover

Commented [SJ25]: Accepting oneself after the stroke

Commented [SJ26]: Anxieties about fulfilling future responsibilities

Commented [SJ27]: Limitations

Commented [SJ28]: Appreciating small accomplishments; help to motivate and encourage; source of hope

Commented [SJ29]: Emotional Support; parents were strong for participant

Commented [SJ30]: Parental Support; Emotional Support

Commented [SJ31]: Parental Support; Support provided motivation

Commented [SJ32]: Support from friends and family

Commented [SJ33]: Positive Energy and positive thinking; encouraged when down; provided strength to keep fighting

Commented [SJ34]: Support motivated and encouraged throughout recovery

Commented [SJ35]: Support for parents; parents' experience of participants' stroke; parents were going through the stroke as well; parents' anguish

Commented [SJ36]: Parents' experience of participants' stroke; External Support for parents from family and friends

Commented [SJ37]: Parents' experience / anguish motivated participant to work harder

would read these out. It kept me staying positive. My boyfriend was overseas, he wrote to me. This was important to me for him to write and keep in touch and think about me. When he phoned my mom held phone to my ear, but I was so emotional, I couldn't speak back to him, but it was nice to hear him. After that he wouldn't accept me because I didn't recover fully. I was angry he didn't come back when I had the stroke. I wasn't accepting myself because of him, so I had to leave. I see the stroke as a journey, it showed me what was best for me, and it wasn't him. Now I'm stronger, and confident.

What changes or challenges did you face and how did this make you feel?

Everything I did was a challenge, from as small as changing clothes to trying to drive a car. My life has never been the same since but as I said I wouldn't change a thing as I'm a better, strong person. It was a challenge to let him go to accept myself. I was depressed and angry – I wasn't liking how I was acting. I was rude and upset. I didn't get along with stepmom before but now it got worse. I had to let go of that anger. I couldn't walk, talk or eat.

My attitude to life is now different. I'm not as afraid to confront. I also let things go a lot easier, I am more forgiving. I don't get embarrassed easily any more. I don't let others take over me because now I am much more confident. My mom was the thing that made me stronger. I overcame the stroke. I made a conscious decision in my mind to not let people affect me and pull me down. My mom kept saying there are greater things for me. Christianity played a role. God had better plans for me. Mom was strong, and I drew on her strength and needed her to be strong for me. She broke down after I was home. She was strong for 3.5 months. When everything was going good for me that's when she broke down then.

What recommendations would you make for other young adults who have had stroke?

My case was very different to people who are prone to strokes but all I can say is that you need people that will support you, be there for you and just really not judge you for how you are after the stroke. I had a boyfriend at the time and he just couldn't accept me the way I was which meant I couldn't accept me self. I broke it off with him as I needed to if I was going to live a good and happy life. He was a good man, just not the person for me. What I'm trying to say is you need to make sure you get out all the negatives in order for you to have the strength to get better.

I was like a baby. I couldn't do anything. I had to learn it all. It was very emotional. You need help and support of loved ones who will be there for you no matter what. And with financial support, I was lucky.

Commented [SJ38]: Positive Energy / Positive thinking

Commented [SJ39]: Emotional; limited abilities also contributed to emotions

Commented [SJ40]: Acceptance post-stroke

Commented [SJ41]: Felt abandoned, unsupported by boyfriend at the time

Commented [SJ42]: Acceptance post-stroke; Ending of Relationship

Commented [SJ43]: Stroke as Journey; learned what needed to changes – shown by stroke what changes needed to be made; Learning experience, Better post-stroke

Commented [SJ44]: Stroke as a Journey; life changing experience; now a better and stronger person; stroke strengthened participant as a person

Commented [SJ45]: Accepting oneself post-stroke

Commented [SJ46]: Depressive symptoms; Anger

Commented [SJ47]: Frustrated with self, own behaviours and short-comings

Commented [SJ48]: Limitations

Commented [SJ49]: Positive energy post-stroke

Commented [SJ50]: Attitude change due to stroke; life changing experience; easily forgives

Commented [SJ51]: Support from Mom

Commented [SJ52]: Kept thinking positive thoughts

Commented [SJ53]: Religion as a Support

Commented [SJ54]: Parents' experience of participants' stroke

Commented [SJ55]: Need for Support; Need to not be judged; need for acceptance from others

Commented [SJ56]: Important to accept self after stroke

Commented [SJ57]: De-clutter life of negatives – Keep positive thinking and positive energy

Commented [SJ58]: Inability to care for oneself; Felt like a baby; Felt helpless

Commented [SJ59]: Feeling helpless

Commented [SJ60]: Emotional

Commented [SJ61]: Need for Support

Commented [SJ62]: Supported financially; blessed for having parents attend to medical expenses; made recovery easier to not have to worry about medical bills

I did feel judged by my boyfriend at the time. When I couldn't do things he judged me. My boyfriend now waits for me to ask if I need him to open jars etc. My ex-boyfriend got frustrated when I couldn't do things – got irritated with me. Pushing trolleys or taking long to do things. It made me feel like something was wrong with me. I couldn't be with people who would not encourage me.

Commented [SJ63]: Feeling Judged by others

Commented [SJ64]: Others became frustrated with physical limitations; feeling unaccepted due to physical inabilities

Commented [SJ65]: Judged by others due to limited abilities

Commented [SJ66]: Need to surround self with positivity

APPENDIX I

Emerging Themes and Direct Quotes from Sample Transcript

1	Shock / Surprised response	It was a shock to me. Went in for something else, came out with a stroke. Didn't register what a stroke is Couldn't talk for 3 weeks. Trained muscles in throat and mouth to learn to talk
2	Loss of physical ability And physical limitations Being voiceless	In my siltation I had lost a lot of weight and muscle from lying on the bed for three and a half weeks. This meant I couldn't walk, talk or swallow. I could only voice my feeling after about 2 weeks when my voice came back. I couldn't speak at the time. could not sit up on my own, needed help to get seated on my bum. They would sit me up and I would fall over. Had to strengthen my core. Was worried I would never walk again. I couldn't speak. Couldn't talk for 3 weeks. Trained muscles in throat and mouth to learn to talk. Was difficult. Cried in rehab. could only voice my feeling after about 2 weeks when my voice came back. I couldn't speak at the time. Had all the feelings bottled inside. Could not get answers I needed. Very confused and overwhelmed. I couldn't express my feelings at the time. Or asked questions. Wanted to know what else could I do to recover? Voice came back and then went away for 2 days. Very scary time – thought I wouldn't speak again.
2	Experience of helplessness Anxiety:	I was like a baby. I couldn't do anything. Had to learn it all. Was very emotional.

4	<p>Regaining normalcy Walking again Being accepted into the world Returning to work Speaking again Being judged on physical appearance Fulfilling responsibilities (present and future) Physical health, constant worry about reoccurrence and other ailments Stroke reoccurrence – being unable to determine if it is happening again</p> <p>Judged → Physical limitations Concern regarding being judged due to physical appearance Abandoned by boyfriend He did not understand her limitations post-stroke Intolerant Impatient</p>	<p>Would I be normal? Would I be accepted into the world? Would I look the same? Very conscious about how I looked to others? Would I be able to work again? I thought about my future, would I be able to look after my children?</p> <p>. When I did realize I was scared and worried if I was ever going to be able to be normal. In my situation I had lost a lot of weight and muscle from lying on the bed for three and a half weeks. This meant I couldn't walk, talk or swallow. I could only voice my feeling after about 2 weeks when my voice came back.</p> <p>I do not remember the feeling of having a stroke. If I had to have one now, I wouldn't know what it feels like. My boyfriend watches me. I tell him about any little feeling I get anxious, any new feeling I tell people and they watch. Was worried I would never walk again. I couldn't speak</p> <p>I did feel judged by B/F at the time. When I couldn't do things he judged me. BF got frustrated when I couldn't do things – got irritated with me. Pushing trolleys or taking long to do things. It made me feel like something was wrong with me. I wasn't accepting myself because of him. I had a boyfriend at the time and he just couldn't accept me the way I was which meant I couldn't accept me self.</p>
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5	Frustrations	<p>Beginning – went through every emotion. Laughed a lot. Then cried so much. 3 weeks depressed. Then very angry. It was a shock to me. I couldn't speak at the time. Had all the feelings bottled inside. Could not get answers I needed. Very confused and overwhelmed. Depression and anger – wasn't liking how I was acting. I was rude and upset. Didn't get along with stepmom before but now it got worse. Had to let go of that anger. Couldn't walk, talk or eat.</p>
6	<p>Working in the present</p> <p>Appreciating small accomplishments – provided hope, lifted mood and encouraged to keep going</p> <p>Difficulty seeing the future – focussed on the pain and limitations</p> <p>Using age / youth to help in recovery process</p>	<p>Rehab was so hard. U do not see the future. Just focused on the moment – which was very painful and difficult. Could not move fingers when left the hospital. Could not even twitch.. when it twitched for the first time it just gave me a lot of hope. Small improvements at the start mean so much when u feel down</p> <p>Could draw on being young – previously vibrant. Gran in her 60s recovered fully from her stroke. So I had to make sure I walked out of that rehab centre. Everyone kept saying age was on my side. So this gave me hope.</p>
7	Parents' experiences	<p>Everyone visited me, from far. People supported my family and this meant a lot to me because they also went through this with me. Was worried about how my family felt. Luckily others were there to lift them up. Docs told parents to prepare for the worst, mom prayed and felt calm. When she told me this it motivated me further to</p>

		learn to walk etc. Mom was strong, and I drew on her strength and needed to be strong for me. She broke down after I was home. Was strong for 3.5 months. When everything was going good, she broke down then
8	Importance of support: Physical, Emotional, Financial Religious Family	could not sit up on my own, needed help to get seated on my bum. They would sit me up and I would fall over. I had emotional support as well which helped me. parents were by her side throughout. Mom was there every minute. Laughed with me and let cry. Held me when I needed to cry. Siblings were so supportive. *** began crying*** mom was my rock. Love from my family motivated me to get better. Friends were visiting – some of whom I didn't even know. my family was my rock. Without them I would never had had the strength to fight the way I did. Everyone visited me, from far. People supported my family and this meant a lot to me because they also went through this with me. Was worried about how my family felt. Luckily others were there to lift them up. Docs told parents to prepare for the worst, mom prayed and felt calm. When she told me this it motivated me further to learn to walk etc. received letters from overseas. Mom would read these out. Kept me staying positive. Christianity played a role. God had better plans for me. And financial support. I was lucky. My case was very different to people who are prone to strokes but all I can say is that you need people that will support you, be there for you and just really not judge you for how you are after the stroke.
9	Accepting oneself post-stroke	I am not still fully recovered. I have to accept myself the way I am. I was angry he (boyfriend at the time) didn't come back when I had the stroke. I wasn't accepting myself because of him, so I had to leave. Challenge: to let

10	Stroke as a journey / learning experience	<p>him go to accept myself. I had a boyfriend at the time and he just couldn't accept me the way I was which meant I couldn't accept me self. I broke it off with him as I needed to if I was going to life a good and happy life. It has been quite a journey for me, I've gone through many emotions (highs and lows) and iv found it to be very tough and challenging, but once I let myself experience and go through all the emotions I now wouldn't change it for the world!!!! Stroke was a journey, showed me what was best for me, and it wasn't him. Now I'm stronger and confident. My life has never been the same since but as I said I wouldn't change a thing as I'm a better, strong person. Attitude to life is now different. Not as afraid to confront, let things go a lot easier, am more forgiving. Don't get embarrassed easily any more. Don't let others take over her, cos now I am much more confident. Made sure to get out all the negatives in order to have the strength to get better.</p>
11	Positive energy and positive thinking	<p>I had so much positive energy around me and my family was my rock. Without them I would never had had the strength to fight the way I did. They all motivated me. Everyone visited me. received letters from overseas. Mom would read these out. Kept me staying positive. My case was very different to people who are prone to strokes but all I can say is that you need people that will support you, be there for you and just really not judge you for how you are after the stroke. Could not move fingers when left the hospital. Could not even twitch.. when it twitched for the first time it just gave me a lot of hope. . I overcame the stroke. Made a conscious decision in my mind to not let people affect me and pull me down. Mom kept saying there are greater things for me. you need to make sure you</p>

		get out all the negatives in order for you to have the strength to get better. I couldn't be with people who would not encourage me.
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The above table depicts the initial list of emergent themes and the corresponding quotes directly extracted from the original transcript that substantiate the themes.

APPENDIX J

List of Emerging Title Themes in Chronological Order:

Shock

Loss of physical abilities and Physical limitations

- 1) speech
- 2) walking
- 3) muscle mass
- 4) feelings of helplessness

Experience of anxiety regarding:

- 1) Regaining normalcy
- 2) Walking again
- 3) Being accepted into the world
- 4) Returning to work
- 5) Speaking again
- 6) Being judged on physical appearance
- 7) Fulfilling responsibilities (present and future)
- 8) Physical health, constant worry about reoccurrence and other ailments
- 9) Stroke reoccurrence – being unable to determine if it is happening again

Working in the present:

Appreciating small accomplishments:

- 1) Provided hope
- 2) Encouragement to keep going
- 3) Lifted her mood

Being Voiceless

- 1) Feeling trapped
- 2) Unable to verbalise concerns
- 3) Had to bottle feelings...unable to express them due to speech impairment
- 4) Unable to raise questions regarding stroke and recovery

Experience of helplessness

Importance of support

- 1) Physical assistance
- 2) Emotional, encouragement, positive people
- 3) Financial
- 4) Religious
- 5) Family – parental support, strong for her, motivated her to push through arduous recovery process

Use youth / age to draw on strength to recover, make recovery manageable

The experience of accepting oneself post-stroke

Positive energy and Positive Thinking:

- 1) Being encouraged when feelings down
- 2) Gave her strength to fight
- 3) Reflection on how far she already came motivated her to continue working to better self
- 4) Fed off other people's positive energy and their encouragement

Parents' experience:

- 1) Parental concerns – once she gained insight into her experience, she began to realise how the stroke had made her parents feel
- 2) Parents received support from their friends as they supported her
- 3) Experience of parents anguish motivated her to recover

Stroke as a journey / learning experience:

- 1) Journey showed her what needed to change in her life
- 2) Life-changing
- 3) Now a better, stronger person post-stroke
- 4) Attitude change toward life
- 5) Easily forgive
- 6) De-clutter life from negative people and negative energy

Experience of being judged:

- 1) Judged due to physical limitations
- 2) Concern regarding being judged due to physical appearance
- 3) Abandoned by boyfriend
- 4) He did not understand her limitations post-stroke

- 5) Intolerant
- 6) Impatient
- 7) She became angry with his intolerance and realised he was not the right person to help her move forward post-stroke

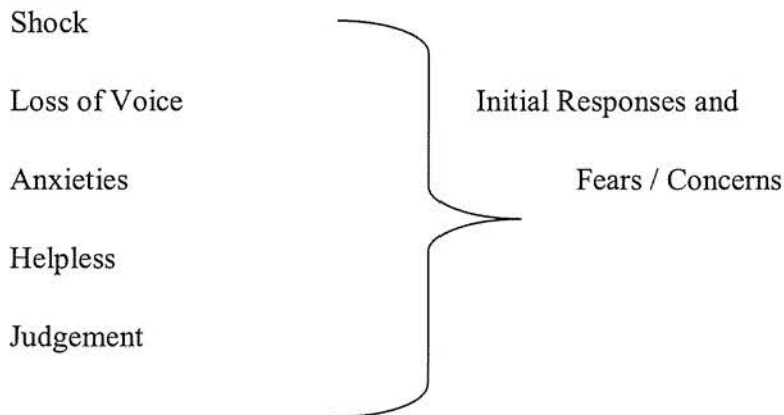
Experience of frustration:

- 1) With self – limitations
- 2) With others – not understanding
- 3) Denial, depression, anger, acceptance

APPENDIX K

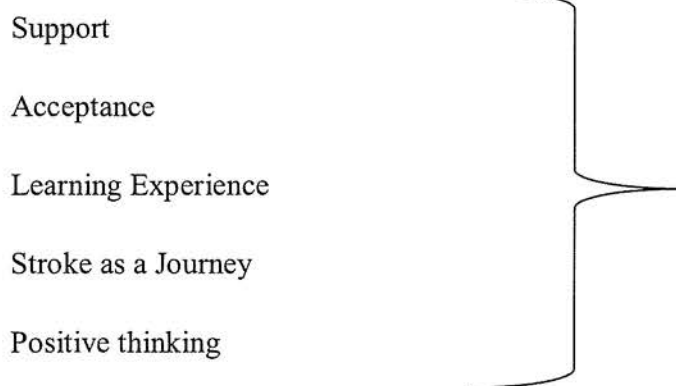
Connecting the Themes

The following is a work up of how themes were clustered into groups for the sample transcript. Certain themes were dropped from the final list of themes as they were not richly supported by evidence in the transcript. Clusters were then given names. Thereafter, analysis of the next transcript began.



Using Youth to help recover

Working in the present



APPENDIX L

List of Emerging Themes

The following is a combined list of themes that emerged from all four transcripts:

1	Denial, disbelief, shock
2	Frustration
3	Helplessness, Dependency, the loss of independence
4	Physical limitations
5	Experiencing loss
6	Anxieties
7	Being voiceless
8	Being judged
9	Experiencing pain
10	Cognitive challenges
11	Medical service received
12	The experience of rehabilitation
13	Keenness to do more to recover
14	Parents' experiences of participants' stroke
15	Working in the present
16	Drawing on young age / youth to recover
17	Importance of support
18	Determination / learning to cope
19	Acceptance post-stroke
20	Importance of positivity
21	Stroke as a journey

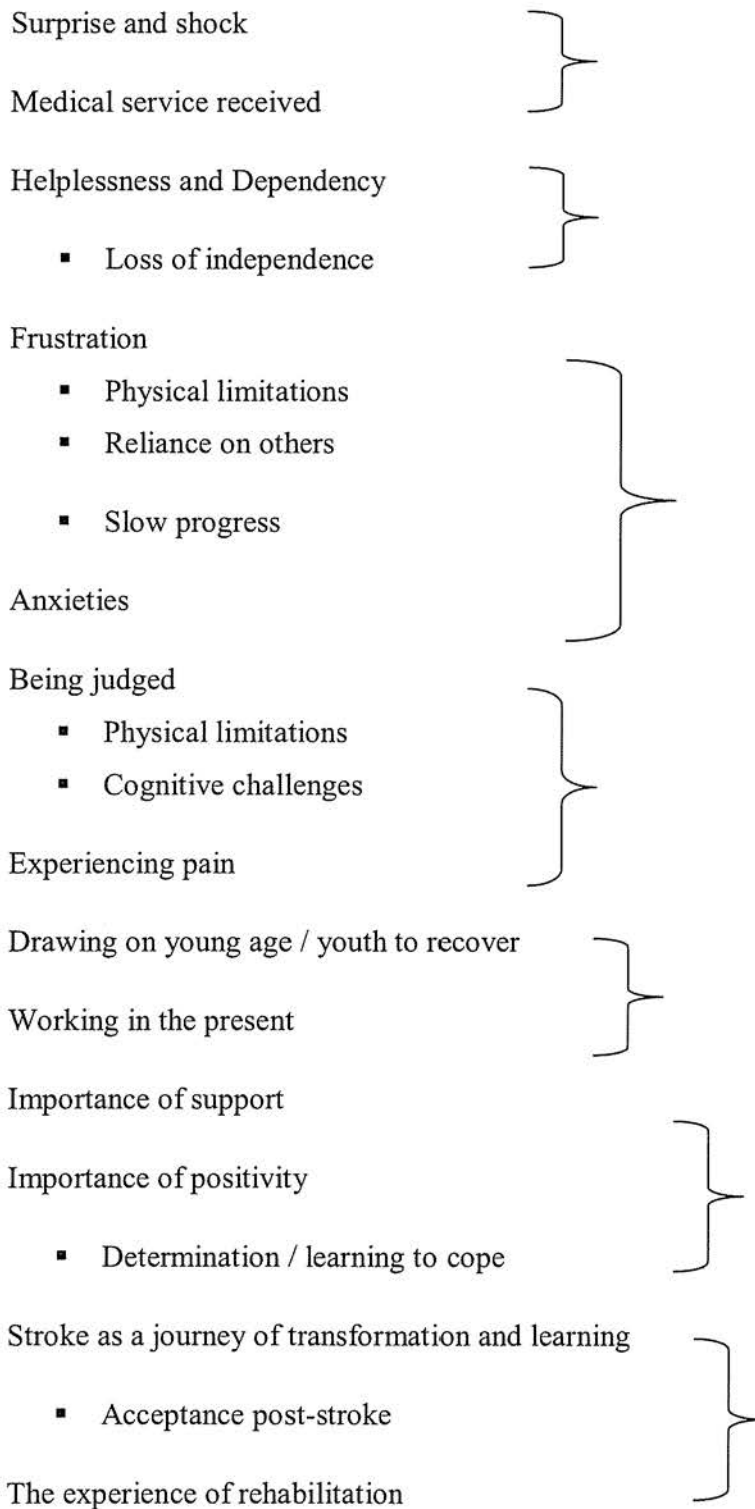
Themes were then clustered together from this table and certain themes were eliminated. Only themes rich in data and of an authentic representation of the participants' responses were selected.

Before a table of Final Themes was drafted all themes that emerged from the four transcripts were clustered and given names, as shown below.

APPENDIX M

Clustering and Naming of Themes

The work-up below shows how the researcher clustered together the themes that were to form part of the Final List of Themes to be analysed.



Experiencing loss

Being voiceless

Keenness to do more to recover

Parents' experiences of participants' stroke



Themes that
were eliminated

APPENDIX N

Master Table of Themes

Below is the modified, final List of Themes, as discussed in Chapter 4.

1. The Initial Response of Shock and Surprise
 - 1.1. Appropriate Response By Medical Practitioners
2. Frustration due to Limitations
 - 2.1 Dependency on others due to limitations
 - 2.2 Frustration As A Result Of Dependency
 - 2.3 Frustration at Slow Progress
 - 2.4 Post-Stroke Frustrations within the intimate relationship
 - 2.5 Temporary loss of Independence
3. Perceived Fear of Judgment
 - 3.1. Being judged on physical Restrictions
 - 3.2. Being judged on restrictive cognitive capabilities
4. The Significant Role of Family Support
5. Stroke as a Journey of Transformative Learning

APPENDIX O

Diary of Contact with Participant (used in sample analysis)

Provided below is a diary containing the details of each contact made with the participant whose transcript is used as a sample. This diary was set up for each of the participants to monitor and record contact between researcher and participant.

Date	Method of Contact	Content of Contact
12/12/2014	Telephone	Introduction to researcher and topic, invitation to participate
12/12/2014	Email	Participant Information; Consent Form; Interview Schedule
19/12/2014	Email	Informed consent signed and returned; Responses received;
19/12/2014	Email	Thanking participant for responses; querying date and time to telephone for follow-up
22/12/2014	Email	Date and time confirmed
22/12/2014	Telephone	Follow Up Interview; Thanking participant for participating in the study, clarify responses, extrapolate further meaning from responses provided.
31/12/2014	Email	Confirming job description and duration at present place of employment
31/12/2014	Email	Participant provides employment information
31/01/2015	Telephone	Provide participant with feedback on study findings

APPENDIX P
Confirmation Letter of Professional Editing Services



DATE: 05/11/15

ATT: To Whom It May Concern

RE: Master's Thesis Editing

This letter serves to confirm that Sumaya Jeewa, ID: 8806170145082, recruited the freelancing and copywriting editorial services of *typeright* for the editing and proofreading of her research dissertation.

Please do not hesitate to contact us for any further queries or information you might require.

Kind Regards,

Karis Leigh

info@typeright.co.za

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